SEER Registry Data Management Project

Process Model Text – Processes and Sources/Sinks

The text is one part of the process model. The other part is the diagram.
The development of this model is in progress, so the following text is incomplete.
SEERSYS\Requirements\Process Models\6 – NP\BPM Registry Operations – Processes NP.doc

First draft: July 12, 2002
Last update: April 17, 2003

Stage: New Physiological (NP)

This model is being developed using a staged approach. This represents the new world of registry operations accounting for facts of life, facts of policy and some facts of implementation only.

Notes to SEER Team:

For processes that interact with Rules or Criteria, need to determine if this is a rules based or parameterized
FieldL – laptop: free standing, disconnected from the CRO. Does not technically have to be a 'laptop' computer. GUI may have to be different from CRO GUI.
FieldH – home: logged in to the CRO, does not have to be a desktop computer. Processes are running remotely on the CRO. GUI may have to be different from CRO GUI. This has to cross the firewall.
Overall DESIGN NOTE: In any process where a person would have to stare at computer screen for a long amount of time, they should be able to print the information (print health record, print patient set, print consolidation screen, print text fields). These people like paper because it's easier on the eyes. However, they need the ability to restrict the printing of information with a password. Probably need to consider verifying that printer selected by user is in a secure location.
Overall DESIGN NOTE: this should be obvious but: 1. Automate as much as possible. 2. Unlimited text fields are a must!

Processes

1.0 Conduct Screening

ID: 1.0

Description

This involves determining the reportability status of records received. For each record, is the cancer/tumor/case reportable? To whom is it reportable? (SEER, local, special study)
Also includes screening for Special Study Reportability, even if non-cancer.
The Field Rep may need to have access to additional medical information to make the determination. This may include obtaining additional demographic information from a data source, i.e. Follow Back. In some cases the Source Document may look like a CTC, but later may be ruled out. If so, the CTC is still accounted for as a non-reportable diagnosis. Records that don't even look like CTCs (or special study) are not kept because it is illegal to do so.
LOCATION NOTE: sometimes the record doesn't come into the registry. The registry staff member goes out to the facility (i.e. a path lab) and screens the records on-site. In these cases, this is the first process that occurs. (Followed by search for patient match and conduct abstracting)
DESIGN NOTE: Opportunity to incorporate rules and use pattern-based technology
DESIGN NOTE: as this becomes more electronic, it will probably be easier to find all CTCs close to diagnosis. This means all CTCs will be 'rapid'.

Processing of Death info:

1. Death list/index is obtained by the registry. It is scanned for new CTCs (passes fine filter for Cancer/Tumor/Case). If true then a death certificate is requested from the state. Some registries may only be doing this if there was no patient/CTC match.
2. The DC is obtained. If the index entry was marked as a new CTC, the DC is screened to verify that it really is a CTC and is then added as an incomplete patient set (or CTC set if patient exists.) In this case, then do follow-back to gather facility information (hopefully an abstract) about the CTC.

Interested Registries

Interested:
Not Interested:

Local Procedures

DT is doing most of this at the facilities. They are trying to find all CTCs within 1 month of diagnosis. They would do '1.3.1 Collect Additionally Required SS Variables' at the same time. They also collect as much info as possible during this task (since they have the medical records, not just a health record). Leads are transmitted to the registry.
UT is similar to DT.
LA & UT are starting to get the Canadian ISIS package installed in some of their path labs. They are getting the screened results and send the information on to the relevant hospitals.
SEA: does 100% casefinding at registry. They tell the facilities what cases they are expected to receive, whether or not they abstract it themselves.
SEA: they call this the pull list algorithm. They retain the excluded records (their hospitals are sometimes interested in records SEA is not because of catchment issues.) The lists are marked as to whether the computer or a person made the decision. The person must provide comment defending decision. The Includes list (reportable) go to through 4.0, 2.0, 5.1.3 and 18.4. The Excludes list go through 4.0 passive follow-up and are retained for QC purposes.
SEA: in the name of QC, the re-run all the case finding records received during the year to make sure that all records were handled appropriately.

Degree of Automation

Fully and Semi

Processor

Case finder/screener
Special Study Manager
Computerized

The following may participate in the role of case finder:
Field Staff (abstractor)
Office Staff
Hospital Staff
Medical Editor
Abstractor/Cancer Registrar
Data Manager

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

If possible, would be nice to allow editing of data at end of this step. However, data was edited in '13.0 Confirm Receipt of Record' and no new information has been added, so editing seems redundant to the designers.

Sensitivity

Trigger

(Acceptable Health Info Arrived – which subsets as:)
Health Record Arrives Electronically **or**
Paper Health Record Deemed acceptable

Metrics

Frequency:
Volume: SEA: screens 154,000 disease index records; 51,000 path reports and 77,000 rad/chemo therapy records per year. NJ: 110,000-120,000 records (30,000-40,000 paper paths, headed towards AIM) – not including correction or follow-up.
Duration: HI: 50 a day per person: screen, check for dups, visual edits, match & consolidate. Manual
Duration: LA: Also Manual, no feel for how much electronic would reasonably expect to do.
Quality/Error rate: LA: suggested contacting **SEA** or **NM** about this
Quality/Error rate: SEA: out of about 350,000 CF records, they find 1500-1700 records that need to be investigated. (dropped inappropriately)

1.1 Conduct Initial Screen

ID: 1.1

Description

This automated process determines the reportability of a record entering the registry for SEER, local, Special Study, etc.
All records that are deemed as not being reportable at the gross screening level, 'Non Cancer/Tumor/Case Records Not Reportable to a Special Study', are discarded for legal reasons. These are records we are sure we don't need. We don't track why they were kicked out.
If a record fails this gross filter, it is still matched against existing patient sets for passive follow-up purposes. If it is useful for passive follow-up, we'll have to keep basic information (Patient ID, Facility ID, Date of Contact) for tracking purposes so we can source the follow-up information to it.
Records that are considered 'boarder line' may be stored with a non-reportable flag and non-reportable reason.
Records that are deemed as reportable are stored and move to either process 3.0 or 4.0
If a record is inconclusive as to whether or not it is reportable, a flag will be set so that the record can be manually reviewed.
Processing of Death Info: Although most health records which fail the broad screen are removed from the data store, DC tape/list/index records are retained in the name of passive follow-up. These are public records.

Interested Registries

Interested:
Not Interested: LA (until records begin to arrive electronically)

Local Procedures

Local differences exist in what is a reportable disease per registry

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

When a record is "kicked out" as "non-cancer/tumor/case and record not special study reportable", and is not used in passive follow-up, we would also want to remove it from the Health and Supplemental Record data store. Death certificates would be an exception to this rule as you would want to keep these for follow-up information for future CTCs that haven't been abstracted yet.

The implementation of this is still to be determined.

Sensitivity

Trigger

(Acceptable Health Info Arrived – which subsets as:)
Health Record Arrives Electronically **or**
Paper Health Record Deemed acceptable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

1.1.1 Determine Potential CTC and Special Study

ID: 1.1.1

Description

This is an automated gross filter to eliminate records that absolutely do not meet reportability criteria. We are filtering out not-reportable diagnoses like broken legs, herniated disks, childbirth, etc. We are examining Converted ICD Codes or unconverted disease text (keywords, including Pathology Reports) in Valid Health Record or Additional Disease Codes + Keywords in Death Certificates to determine if there is a Potentially Reportable Cancer/Tumor/Case Record.

As noted in 1.1, if a record fails the gross screen, it may be used to passive follow-up. Basic information (Patient ID, Facility ID, Date of Contact) would have to be kept for tracking purposes.

Special Study Criteria is considered because there may be some instances where records are not going to pass SEER or Local screening and would otherwise be thrown out. We want to keep these – "Non Cancer Special Study Records".

Can also result in questionably reportable info, if the text phrase is not handled well in the rules. For example, 'definitely not cancer' may confuse the computer, but be perfectly clear to a person. Records of this type should probably result in new rules for screening be considered or added to the Rules.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Health Record Arrives Electronically

Metrics

Frequency:
Volume: LA: currently manually screening about 800,000 paths a year, hope to screen 100,000 paths per year when e-path reporting occurs. Only keeping about 20,000 paths. 50,000 abstract pass screening.
Duration:
Quality/Error rate:

1.1.2 Do Initial Screening for Local/SEER Reportability

ID: 1.1.2

Description

Reviews SEER Reportable List and Local Reportable List to determine if the potentially reportable record is truly reportable either to SEER or locally per SEER and Local rules.
The rules include whether the record is reportable to either SEER or local based on residency and would set the residency status appropriately. If not reportable, then 'not reportable reason' is given per SEER and per local reporting organization.
Note: The Registry determines what goes to each specific organization later, when the data is extracted for reporting.
If the screen is completed successfully, the data is sent to '4.0 Match and Consolidate patient set'. The incomplete patient set information may also be used by '2.0 Conduct Abstracting'.

Interested Registries

Interested:
Not Interested:

Local Procedures

DT: collects CIN3 and CIS cancers.
NM: collects benign brain and non-SEER rpt skin

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Paper Health Record Deemed acceptable **or**
Yes, Potential CTC

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

1.1.3 Do Initial Screening for Special Study Reportability

ID: 1.1.3

Description

An automate process that retains any record that meets the criteria for a any Special Study.

The rules include whether the record is reportable via a Special Study based on residency and would set the residency status appropriately.
A "Potentially Reportable Cancer/Tumor/Case Record "that does not meet the criteria for a Special Study will be retained regardless of the screening result for SEER and Local Reportability – these are deemed are non-reportable to Special Studies.
If record is not potentially reportable to SEER or Local, but passed the broad Special study screen, the special study non-reportable reason may be saved and the record flagged as non-reportable. No patient set will be created. Some registries may choose not to do this and they don't seem to be externally audited on it, but functionality should be available. See Screen for Possible Local & SEER Reportability, 1.2
Since multiple CTCs may be reportable to multiple Special Studies, we need to know which Special Studies the record is reportable to.
If the record is deemed eligible and is part of a rapid case ascertainment special study, then rapid case ascertainment indicator is turned on for the record. For an abstract, this means expedited travel through the rest of the processes. For a non-abstract health record, need to allow a path (15.0, Match Patient Set; 4.0 Consolidate Patient Set; 3.0, Support Special Studies) for those CTCs where an abstract is not needed. In these cases, the abstract will be obtained AFTER record has gone to special study, in normal registry timing.
At completion of 'screen', the incomplete patient information may be used by '15.0 Match Patient Set' or '2.0 Conduct Abstracting'
If Matched non-reportable CTC info passes the screen, this information would go directly to 2.0 and/or 4.0.

Interested Registries

Interested:
Not Interested:

Local Procedures

Local rules may be broader than SEER rules.
Some registries would like to treat this step as the setting of a status flag. All records that made it to this step would be turned into patient sets – with SEER reportable flag and Local reportable flag, both of which may be off.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Currently, one reason there is not a kick out (deletion) of 'non-reportables' because they want to track (if it comes up again) that they've already screened it and deemed it 'non reportable' along with the reason they deemed it 'non-reportable'.
Another reason we keep these records that are kicked out is for QC audit purposes.
Yet another reason we keep these records is that sometimes two records that separately look non-reportable can combine to look reportable (e.g., the first includes a histology that's not reportable; but another record indicates that the histology was wrong, and the CTC is actually reportable).

Sensitivity

Trigger

Paper Health Record Deemed acceptable **or**
Yes, Potential SS Patient & SS exists **or**
Yes, Potential SS Patient & RCA needed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

1.2 Complete Final Local/SEER Screen

ID: 1.2

Description

This manual process reviews records that process 1.1.1 deemed as questionably reportable or process 1.1.2 deemed as inconclusive for Local/Seer Reportability and ultimately decides if the potentially reportable record is truly reportable either to SEER or locally per SEER and Local rules.

The same rules apply as in 1.1.2; however, conversion of free form text may also take place here.

If follow-back is required, a health record update may be generated here to attach the follow-back response to the health record being screened.

DESIGN NOTE: for conversion of codes and selection of keywords (13.4 tasks) which can not be automated, they would manually do those tasks while screening as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Case finder/Screener
Abstractor (in role of case finder)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Computer can't decide if CTC (hence reportable)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

1.3 Complete Final Special Study Screen

ID: 1.3

Description

This manual process reviews records that process 1.1.1 deemed as questionably reportable or process 1.1.3 deemed as inconclusive for Special Study Reportability and ultimately decides if the potentially reportable record is truly reportable either to any Special Study.

If additionally special study variables are needed, they are gathered here. Usually, only additionally variables needed to complete the screen are collected by the registry.
If follow-back is required, a health record update may be generated here to attach the follow-back response to the health record being screened.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Case finder/Screener
Abstractor (in role of case finder)
Special Study Manager

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Additional Spec Study variables needed **or**
Computer can't decide if eligible for Special Study

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

1.3.1 Collect Additionally Required SS Variables

ID: 1.3.1

Description

When a special study requires variables outside of the standard registry collection list, additional effort is required to track down the information. This also includes the collection of additional variables needed to finish the screening task. (Possibly county which is not usually found on path reports)
For some special studies, this process may be concurrent with 2.1 Create Abstract. For others (especially those which require rapid case ascertainment), this could happen as soon as or while the CTC is screened and noted as 'reportable to special study' and the 2.1 Create Abstract would happen months later.
Seems to mostly refer to rapid case ascertainment of path reports.
Usually for variables needed for screening and the special study staff collects anything else they have interest in.
For SEER POC studies, the cohort has been selected and the registry staff has gone back to a facility to gather this information.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA only collects variables that are necessary to complete the screening process (residency, etc).

Degree of Automation

Semi

Processor

Case finder/Screener
Abstractor

Location

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Additional Spec Study variables needed
(Follow-back Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

1.3.2 Make Final Decision Regarding SS Eligibility

ID: 1.3.2

Description

The actual fine screening of a record or document to determine whether or not it is reportable to (or eligible for) an on-going special study.
In the case of rapid case ascertainment, this task may be concurrent or after 1.3.1 Collect Variables to Assess Special Study Reportability.
This manual process reviews records that process 1.1.1 deemed as questionably reportable or process 1.1.3 deemed as inconclusive for Special Study Reportability and ultimately decides if the potentially reportable record is truly reportable to a special study per that study's criteria.
The same rules apply as in 1.1.3; however, conversion of free form text may also take place here.
DESIGN NOTE: for conversion of codes and selection of keywords (13.4 tasks) which can not be automated, they would manually do those tasks while screening as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Case finder/Screener
Abstractor (in role of case finder)
Special Study Manager

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Computer can't decide if eligible for Special Study
(Follow-back Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

2.0 Conduct Abstracting

ID: 2.0

Description

Iterative process of patient data evaluation in order to gather enough information to 1) determine whether we need to create an abstract and 2) create or request the abstract if needed and 3) requesting the medical records.

Can also produce abstract facility leads to other locations (referred from, referred to)

NOTE: sometimes the registry staff member is on-site to do Conduct Screening and Conduct Abstracting. In those cases, the information may need to flow directly from Screening to Abstraction.

In some registries existing patient sets are not available to the staff member while on site.

DESIGN NOTE: for conversion of codes and selection of keywords (13.4 tasks) which can not be automated, registries would manually do those tasks while screening as needed. The balance of these tasks would be done during the Consolidate processes or Conduct Abstracting, as appropriate. Information received at the central registry does not have to be structured as an Abstract before being consolidated.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Processor

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

No patient match for potential CTC **or**
No CTC match for potential CTC **or**
No treatment match for potential CTC

(May be run as periodic batch if most efficient)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

2.1 Create Abstract

ID: 2.1

Description

Reviewing patient medical records; analyzing and summarizing the patient, CTC, facility, and treatment information; creating the data items that go on the abstract. (Medical coding may be occurring here. Corresponds to Convert ICD Codes & Decipher Disease Text. If not in these early tasks, must occur during 4.x.2 and 4.x.3: Consolidate CTC and Treatment Information.)

This is the process of creating the data items that go on the Abstract. At end, may need to provide copy of registry created abstract to facility/organization.

The Existing Patient Set is may be used for reference if we are abstracting a 2nd or subsequent CTC, for example. *Note: some registries do not want existing patient set information available to abstractor*.

In creating an abstract, the abstractor may discover a new facility set for the facility to be abstracted and create that "set" at that point. Or they may discover another facility that needs to be abstracted (referred from, referred to, would create an abstract facility lead).

In creating an abstract, the abstractor may discover that a correction needs to be made to current registry information. (This would imply that the abstractor had all information in registry available to them. Registries that do not give the abstractor all info probably would not have this opportunity.) This may be regarding a prior CTC or so on. Model shows New Patient Set Information data flow going to 4.0 to handle this concept. [They currently generate a correction record and process the change that way so that the patient set can be decomposed if needed (or the correction removed if later information indicates this).]

During creation of abstract, the abstractor might discover that a CTC with a reportable status is actually non-reportable. For example: A CTC is labeled carcinoma but after review of the entire medical record, it turns out not to be a CTC. They may discover some new info and need to change/update patient set information. In some cases, the abstractor may need to follow back first.

If treating/diagnosing/etc. facility isn't known (e.g. only the reporting facility), then will do an abstract for the reporting facility; it would be a complete abstract but not a complete Patient Set (pending the treating/diagnosing facility abstract).

Looking at more than just medical charts/files. Could be a single x-ray report or CT scan report. Looking at the reports and charts/files may generate Abstract Facility Leads.

We will not store, in any way, the x-rays or CT scans themselves. If the reports are electronic, we may want to attach them to the abstract.

Need for dynamically create follow-back query.

Check for outstanding follow-back needs for this patient and attempt to resolve them. Ideally, this would include follow-back spawned from any process.

This also includes reviewing the Patient Medical/Vital Records to update follow-up information

It is possible to not be able to complete the abstract. In these cases, the 'date attempted' and 'reason not abstracted' are documented.

Some medical coding happens here – site, type, treatment, extent of disease. This is performed using data from the medical records and putting the corresponding codes on the abstract. This coding was not possible in 13.4 as some of the information is not available until now.

Possible scenarios when creating an abstract:

- New Patient
- Existing Patient/Existing CTC/Incomplete Facility
- Existing Patient/Existing CTC/New Facility
- Existing Patient/New CTC

Design Consideration

Do not actually need the physical entity 'abstract record'. This information can be placed directly in a patient set template. However, they will wish to be able to print patient set info in an abstract layout.
Establish Standard Abstract Template. (This could be defined locally.)
Have abstractors key, scan, or speak the attributes required.
Allow system to generate the physical entity 'abstract'.
Incorporate rules as much as possible for 'editing', 'coding' and possibly even 'extraction.' The editing that occurs here is field edits during creation and inter-field edits either on-going or when abstractor is 'done'. Editing is occurring here as the abstractor is gathering the information. We assumed that the edit process would have the entire abstract (as created up to that point) available. (i.e., enter name – edited for non-alpha characters, enter gender – edited for valid code, consistent with name, enter site – edited for valid code, consistent with gender, enter hist – edited for valid code, consistent with site, consistent with gender, so on)
Ability to generate correction record for processing. Registries wish to avoid on the fly correcting to obtain better tracking (a record to link to) and to retain the ability to decompose the patient set. This could be implemented in a different way if needs can be met.
Should allow for facility accession number assignment at this point. Not all registries will choose to do it here. See also 4.5.2 Assign IDs
From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. Abstractors need to be able to type information in (its quicker in their point of view), but could have auto complete or codes attached to text.
If rules for Abstracting are on line, they would like a mechanism to pull up the correct manual based on the year of diagnosis. (For Dx year=2002, use ROADS; if Dx year = 2003, use FORDS)
Need to be able to print abstracts. (CT loads abstracts electronically, and then prints them for the codes to review)
SEER requires that the abstract be coded based on the year of diagnosis. Current vendor tools force the coding to be based on year of abstraction. May want to allow both settings??
Unlimited text fields, unlimited text fields, unlimited text fields.

Interested Registries

Interested:
Not Interested:

Local Procedures

Many local procedures
Data items collected and structure may vary from registry to registry and hospital to hospital.
Seattle, New Mexico, Iowa: The source documents used to identify need for and to supply content of abstract are held until abstract is created. All of the documents – sources and abstract – are associated (or linked) before releasing from laptop and becoming available as a patient set with the matched records.
Seattle, UT: uses partial abstracts (electronic pathology reports) where appropriate to generate shell of patient set.
Several registries: Create computer-generated abstracts. Will attempt to provide this to all registries.
Some registries want any existing patient set information available to the person creating the abstract (maybe just the facility view, maybe the registry view). Includes DT, UT, NM. Others do not want this, as it may bias interpretation of new records.
DT creates abstracts for several hospitals (contract hospitals). They collect and QC the ACoS variables for these hospitals. They apply

SEER rules in preference to ACoS rules for those variables which overlap.
ATL: mostly in small hospitals without abstractors. In some cases, the medical record is mailed to the registry. They do the abstracting in the registry building, retain the abstract and destroy/return the medical records after a 6 mth holding period.
LA and probably other CA registries use CNEXT because it's provided free of charge. Any system would have to meet state specifications.
HI: recommended reviewing PCDash in NM

Degree of Automation

Semi

Processor

Abstractors (these may also be known as coders)
(*out of scope: Cancer Registrars)*

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Coding is involved here – the Translation of data from text to codes.
'Editing' is involved here. Field & Inter-field. (Inter-tumor edits are merely a subset of inter-field edits run when the entire patient set is available.)
Transmission and confidentiality rules
Data destruction rules
Rules of information use
A goal would be to minimize re-keying at this point
Will be occurring on laptops and desktops; could be on the server *but not necessarily*
Multiple agency rules (often conflict)
There are SEER-required fields
Some registries want to prevent/restrict the input to 'Patient Medical Records' only. I.e. exclude existing patient set and incomplete patient set information. Just have identifiers so the abstractor knows what to abstract.

Sensitivity

Trigger

Information available for required abstract

Metrics

Frequency:
Volume: LA: 3000 per year (if they need to catch up, it's greater)
Volume: HI: 2500 per year
Volume: HI: **spawn follow-back about 90% of abstracts**
Variability: HI: probably changes quarterly to yearly. They hope the changes become less frequent (more changes would happen at the same time)
Duration:
Quality/Error rate: HI: current problem with multiple abstracting of same CTC due to poor synchronicity btwn laptops and CRO. Usually occurs when abstractor doesn't turn CTC in immediately.

2.2 Schedule Abstraction

ID: 2.2

Description

Assign the creation of an abstract to be done at a specific facility. Can be assigned to either one abstractor or a group of abstractors who routinely visit the facility.
This could be the abstracting supervisor assigning abstracts to the staff or a single abstractor determining when leads will be abstracted.

Don't need the whole patient set at this point but need enough to know what needs to be abstracted (the patient identifying info, the CTC identifying info and the facility identifying info).
If treating/diagnosing/etc. facility isn't known (e.g. only the reporting facility), then will do an abstract for the reporting facility; it would be a complete abstract but not a complete Patient Set (pending the treating/diagnosing facility abstract). THEREFORE: abstractor is assigned based on reporting facility.
Circuit riders visit facilities on a fixed schedule and would need/like to abstract as much as possible when there.

Interested Registries

Interested:
Not Interested:

Local Procedures

DT circuits are once every 3 months.
IA has circuits that are once every 6 months or once every year. (very few CTCs obtained.)

Degree of Automation

Semi

Processor

Abstract Manager
Abstractor

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Abstracts to be created can be prioritized by various scheduling criteria including diagnosis date, reporting hospital, etc.
Rapid Case Ascertainment (RCA) increases the priority of any abstracts to be created.
Need ability to batch processing the abstracts.
Need ability to Manage Abstractors trips – part of scheduling criteria. In some registries with wide, hard to get to places (NM especially), registry schedules a 'circuit' and needs to plan: which abstracts from facility, order of facilities, travel time/accommodations, etc. (noted in Manage Cancer/Tumor/Case Information Acquisition 10.2)

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume: HI: increasing every year. LA: increased a lot this year b/c hospitals are behind. Generally increasing.
Volume: LA: 40 registry abstracted hospitals (120 total). Also have several doctor's offices, etc.
Volume: HI: about 2500 abstracts are done by registry
Duration: HI: < 4 hours?
Quality/Error rate:

2.3 Request Patient Medical Records

ID: 2.3

Description

Submit request for patient medical records to a specific facility based on abstracts assigned to abstractor.
All patients to be abstracted during a visit are requested.

In order to create an abstract, the abstractor must have all the patient medical records. When a SEER registry staff member creates an abstract for a facility/org (usually off-site), they request the medical records for the patient they wish to abstract prior to going to the location. This helps increase productivity off-site. Also, since these records are secure, requesting prior to arrival prevents delays due to red tape.
Note: this isn't a byte file they are trying to acquire, it's usually a bunch of papers stapled/paper-clipped together in a folder.

At this point the patient medical record might contain a lot of information or just a little bit of information.
Information from these records may be used on the Abstract, but the records themselves are not necessarily maintained in the registry database. Frequently the hospital will not allow you to remove patient records from the records area.
Note: The potential exists for the request(s) to be automatically generated once patient sets to be abstracted are identified.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM and UT send letters
HI: by phone or fax
LA: by fax, mail, email; field staff may bring list for next visit with them
Must be secure

Degree of Automation

Semi

Processor

Abstractor
Death Clearance Manager
Office assistant (task is clerical in nature)

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

May go through this process in a batch (all medical records needed by abstractor for a particular visit are requested at once.)

Sensitivity

Trigger

Approximately x Days before scheduled abstraction date (amount of notice needed varies by registry and facility) **and**
Abstract required from facility we abstract for

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

2.4 Request Abstract

ID: 2.4

Description

Submit request for abstracts to be submitted from a specific facility using facility contact information. Would only go to facilities that routinely do their own abstracting.

Note: The potential exists for the request(s) to be automatically generated once patient sets to be abstracted and the facility to abstract from have been identified. See 2.6.2 Automatically Request Abstract.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Office Assistant
(task is clerical in nature)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Abstract required from facility which sends abstracts **and**
Not set up to request electronically

Metrics

Frequency:
Volume: LA: ~75 self reporting hospitals (120 total)
Volume: HI: about 7500 abstracts are done by hospitals
Duration:
Quality/Error rate:

2.6 Make Abstract Determination

ID: 2.6

Description

Review match-completed patient set info and abstract facility leads to see if abstract is needed per abstract criteria and depending on existing patient set(s) and existing non-reportable information, if any. Match-completed patient set info would include unmatched incomplete patient set info (no matches) and matched incomplete patient set info including patient- and patient+CTC-matched correction records.

A facility-matched correction record matched to non-reportable record would mean the non-reportable record would have to be re-screened if the correction was to CTC data (the correction might affect the reportability of the original record, information on correction record taken into account). Reportability also affected by address of patient.

Otherwise, these types of records would be excluded from this process.

In other cases, review 'abstract leads' OR 'other facility referenced' to see if the abstract need is already known. (This instance may be part of 'Manage Abstract Facility Leads').

The Existing Patient Set may be needed for reference if we are abstracting a 2nd or subsequent CTC, for example and to make sure we don't already have the abstract in question.

During this evaluation against matched patient sets and non-reportable records, the review might discover that a CTC with a reportable status is actually non-reportable. For example: A CTC is labeled carcinoma but after review it turns out not to be CTC. The record is flagged as unreportable and reason is saved.

BASIC CRITERIA: If the match is at the patient, CTC and facility level, most likely, only the 4.2, 4.3, 4.4 Consolidation processes are performed.

An abstract is not needed if this CTC has already been abstracted.
Need to close the Abstract Facility Lead. If there isn't a facility match (regardless of other match statuses), or there isn't a CTC match (regardless of other match statuses), an abstract needs to be created for this facility.

Example: Patient match, CTC match: registry knows about CTC, but facility has not yet turned in abstract
Example: Patient match, facility match: facility has had patient for other CTCs, but has not turned in an abstract for this CTC yet.
Example: No match: new patient/CTC to registry. Facility needs to turn in abstract.
Example: Patient match: new CTC to registry. Facility needs to turn in abstract
Example: Patient match, CTC match, Facility match:
Abstract already completed: go directly to 4.0, stop 2.0 processing
No abstract: for example, a large hospital with internal lab has sent the registry a hemotology report and a discharge index both in relation to the patient/CTC. However, no abstract has been done and more information is probably available. Can do 4.1 (consolidate facility view) and the rest of 2.0

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully
Semi on Field Laptop for 2.6.1

Processor

Computerized
(Abstractor initiates in IA)

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

No patient match for potential CTC **or**
No CTC match for potential CTC **or**
No facility match for potential CTC **or**
Periodic: a batch of 'abstract facility leads' is processed at one time.

Metrics

Frequency: LA: semi-annual for most hospitals, quarterly for large hospitals.
Frequency: HI: do prior to visit to hospital
Volume:
Duration: LA: ongoing HI: ongoing
Quality/Error rate:

2.6.1 Determine if Abstract Needed

ID: 2.6.1

Description

This process determines if an abstract is needed for a particular Cancer/Tumor/Case. Ideally there would be an abstract for each facility that knows of a given Cancer/Tumor/Case.
Abstract facility leads may be closed if abstract has arrived between the time lead was created and the time the registry would have created the abstract.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation
Fully in CRO
Semi on field Laptop

Processor
Computerized
(Abstractor initiates in IA)

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
No patient match for potential CTC **or**
No CTC match for potential CTC **or**
No facility match for potential CTC **or**
Periodic: a batch of 'abstract facility leads' is processed at one time.

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

2.6.2 Automatically Request Abstract

ID: 2.6.2

Description
If an abstract is needed and the facility is able to produce its own abstracts, the computer automatically requests an abstract to be sent.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor
Computerized
IT
(task is clerical in nature)

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Auto-send letters

Metrics
Frequency:
Volume:
Duration:

Quality/Error rate:

2.7 Add or Modify AFL

ID: 2.7

Description

When a new abstract facility lead is found and needs to be entered or an existing AFL needs to be modified, it may be done here.
Audit logs may be kept of changes to the AFLs.

Interested Registries

Interested:
Not Interested:

Local Procedures

HI and IA are interested in audit logs.

Degree of Automation

Semi

Processor

Abstractor
Abstraction Manager

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

New AFL info received
Abstract received (from 2.6)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

3.0 Support Special Studies

ID: 3.0

Description

This includes the various processes needed to supply the data needed by Research for special studies and to retain relevant data supplied by Research about special studies.
Supplemental Records may be used – not always – as controls.
Data and staff that are used to do this overlap with normal registry operations
NOTE: Special study may come back after a period of time and wish to re-link to Registry data to do a longitudinal study. This does not appear to be currently modeled.
NOTE: Some registries contact Medical practitioner to see if ok to include patient and then contact Patient to see if they wish to participate. Others make the special study staff do this.
NOTE: If patient contacts registry and asks to be removed from Study, registry will contact Special Study group to do so. Would imply an update to the patient set data – some variant of 'do not contact' and an update to the special study data tracking. Could be done via '10.10 Update Patient Set With Randomly Obtained Knowledge'.
STEPS involved in this Process:

Screen: If study is looking for new data, this should have been done in '1.1.3 Do Initial Screening for Special Study Reportability' and '1.3

Complete Final Special Study Screen'. All the process would have to do is look for Health Record info or Patient Sets with the correct Special study ID. If study can use existing data, this process must perform the screen itself. It needs the health records and patient sets that are available as well as the special study criteria and any local rules that apply. (This may also be screening Supplemental record information to use as controls)

Obtain approval: If patient contact is needed for special study, approval is needed. First, get approval from physician to contact patient (may be passive assent), then get approval from patient to be a participant in study. Patient information may be stored in patient set or health record at this point. **This is usually done by special study staff, but may be done by registry staff.**

Select (data group): After determining which data groups are eligible for study, and are willing to participate, select those which will be sent/used in study. This may potentially be all eligible CTCs. Current implementation for selecting partial group is to assign a random number to data group and then select first x records. Mark records as included in study. **This is usually done by special study staff, but may be done by registry staff.**

Match to Patient Set/Supplemental Records – to give best information and let them know who has already died.

Create file: or select data items. This should be very similar to creating an extract of these data groups for the needed data items by process 12.0. Data groups (health record info, patient set, supplemental record info) and special study criteria are needed. Some registries then verify the file against the criteria to make sure selection parameters were correct. This could be actually viewing the records or running frequencies on the selected records. (preventing human error in selection set-up)

Send data: Transfer information to the Special study group and retain date sent to study.

Interested Registries

Interested:

Not Interested:

Local Procedures

LA, HI, and IA immediately send Reportable Records with Special Study Status of "Y' to RESEARCH. (probably accurately describes SEA too)

SEA: since they do not have adequate funding for their case load, Seattle is a minimalist registry. They send the Path reports to the SS group as soon as they pass screening and have a site code assigned. The records have not been matched at that point.

For most registries, obtaining additional demographic information is only done for special studies (LA, IA, NCCC, HI, NM, DT, CT. All?)

	LA	DT	HI	IA	UT	NM	AT	SEA
gather cases	Y	Y	Y	Y	Y	Y	Y	Y
SS vars	N	path rpt # only		Y	N	N		Path rpt only
approvals (MP, PAT)	N	N		Y	Y	N		N
random selection	N	Y		Y	Y	N		N

Degree of Automation

Processor

Special Study Manager

Registry Manager

IT staff
(out of scope: Registry Manager and PI help develop Special Study contracts)

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Data due for special study (data going out) **or**
Special study communication received (data/questions coming in)

Metrics
Frequency:
Volume: LA: 20 new per year; about 30 total ongoing; probably ¼ - ½ use existing data. Increasing numbers
Volume: HI: more than 20 per year. About ½ use existing data only. Increasing numbers
Duration: LA: 1 ½ to 2 FTEs gather and track info released to special studies.
Quality/Error rate:

3.1 Initiate Special Study Selection

ID: 3.1

Description
This process starts the collection of CTCs for a special study.
Gets special study information so it is available for processing and assigns task if necessary.

Interested Registries
Interested:
Not Interested:

Local Procedures
NM: always checks with PI and Dr. Key prior to sending data that everything has been approved.
ATL: done by registry staff. Questions usually resolved by editors or registry DB directly. Most studies are within university.

Degree of Automation
Semi

Processor
Special Study Manager
Registry Manager

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Data due for special study

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.2 Select Patient for Special Study

ID: 3.2

Description

Selecting which patients are to be included in (sent to) which special study. This may include screening patient sets for special studies which need existing patient sets. For studies which use new patient sets, the patient sets should have a special study indicator and special study ID included in the patient set. Include selection of supplemental records where necessary. Potentially includes random sample selection.
Not re-screening health records at this point. Looking for the CTCs with the reportability flags set (i.e. the ones that were deemed eligible).
Narrowing of eligible CTCs to the number of CTCs to be sent/included.
CTCs are determined to be eligible in screening (case finding) and then are selected here in 3.2
CTCs identified as eligible may not be included in the study. This may be caused by inclusion in other studies or more CTCs eligible than required.
For each patient set selected, indicate in which special study it is included.
If special study in question needs rapid case ascertainment, if an abstract is received or the special study does not require an abstract, registry would do the following processes with high priority: 13.0, 1.0, 4.0, 3.0: receive record, screen for reportability (must pass for this study), match to current patient sets (to verify patient not involved in other studies and get most info available quickly) & consolidate patient set (if possible, assign ID if new patient), 3.0 (to send record to study). 4.0 may be replaced in this sequence by '3.4 Match and Consolidate Patient Info'.
For Rapid Case Ascertainment, if record in question was not an abstract, the timing of the 2.0 process would depend on the information required by the special study. If an abstract were needed, the record would follow a normal route with high priority. If an abstract was NOT needed, the route above would be followed and the abstract would be obtained after 3.0 (in timing normal for the registry)
NOTE: will need to know the number sent for billing purposes.

Screen: If study is looking for new data, this should have been done in '1.1.3 Do Initial Screening for Special Study Reportability' and '1.3 Complete Final Special Study Screen'. All the process would have to do is look for Health Record info or Patient Sets with the correct Special study ID. If study can use existing data, this process must perform the screen itself. It needs the health records and patient sets that are available as well as the special study criteria and any local rules that apply. (This may also be screening Supplemental record information to use as controls)
Select (data group): After determining which data groups are eligible for study, and are willing to participate, select those which will be sent/used in study. This may potentially be all eligible CTCs. Current implementation for selecting partial group is to assign a random number to data group and then select first x records. Mark records as included in study. **This is usually done by special study staff, but may be done by registry staff.**

Interested Registries

Interested:
Not Interested:

Local Procedures

When there are more possible CTCs than requested CTCs, registries are using random number selection to choose CTCs to select. (Implementation)

Degree of Automation

Fully

Processor

Computerized
IT Staff may need to set up programs to run.

Location

Central Registry Office

Policies/Business Rules

If interview is required, each patient can only participate in one special study per local policies.

Sensitivity

Trigger

Special Study Initiated **or**
Controls requested **or**

Approval obtained **and**
Random sample desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

3.2.1 Select All Patients Marked Eligible for SS

ID: 3.2.1

Description

If study is looking for new data, screening should have been done in '1.1.3 Do Initial Screening for Special Study Reportability' and '1.3 Complete Final Special Study Screen'. This process lookd for Health Record info or Patient Sets with the correct Special study ID.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Special Study Initiated

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

3.2.2 Screen Existing Patient Sets for Eligibility

ID: 3.2.2

Description

If study can use existing data, this process must perform the screen for special study eligibility. It needs the health records and patient sets that

are available as well as the special study criteria and any local rules that apply.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Fully
Processor
Computerized
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Special Study Initiated
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.2.3 Select Controls for Special Study

ID: 3.2.3
Description
Some special studies are case/control type studies. Control records are those people who have been selected to represent the population at large without the disease/problem of interest.
They are typically from the supplemental records, but it depends on what the study is.
This process is the screening or random selection of Supplemental record information to use as controls.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Fully
Processor
Computerized
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Controls requested **and**
Special Study Initiated

Metrics
Frequency:

Volume:
Duration:
Quality/Error rate:

3.2.4 Select Random Sample

ID: 3.2.4

Description

Select (data group): After determining which data groups are eligible for study, and are willing to participate, select those which will be sent/used in study. This may potentially be all eligible CTCs. Current implementation for selecting partial group is to assign a random number to data group and then select first x records. Mark records as included in study. **This is usually done by special study staff, but may be done by registry staff.**

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully
Manual

Processor

Computerized
Special Study Manager
IT Staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Approvals obtained **and**
Random sample desired **or**

Approval not required or SS responsible **and**
Random sample desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

3.3 Obtain Special Study Approvals

ID: 3.3

Description

If patient contact is needed for special study, approval is needed. First, get approval from physician to contact patient (may be passive assent), then get approval from patient to be a participant in study. Patient information may be stored in patient set or health record at this point. **This is usually done by special study staff, but may be done by registry staff.**

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Processor
Special Study Manager
Special Study Staff
(Task is clerical in nature)
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Approval required
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.3.1 Obtain Physician Approval

ID: 3.3.1
Description
Special studies which include patient contact need to seek physician approval before they contact the patient.
Some registries consider passive consent to be adequate (physician doesn't call to object).
This is usually done by special study staff, but may be done by registry staff.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Special Study Manager
Special Study Staff
(Task is clerical in nature)
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Approval required
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.3.2 Obtain Patient Agreement

ID: 3.3.2
Description

Special studies which include patient contact need to obtain patient consent before they interview the patient.
This is usually done by special study staff, but may be done by registry staff.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Special Study Manager
Special Study Staff
(Task is clerical in nature)
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Approval received (active or passive) (from physician)
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.4 Match and Consolidate Patient Info.

ID: 3.4
Description
Match to Patient Set/Supplemental Records to give best information and let them know who has already died.
Interested Registries
Interested:
Not Interested:
Local Procedures
LA: doesn't do this currently, but wants to improve the process. If this were more automated, they would use it. They do not send CTCs to multiple studies, (about 80% only have 1 CTC), so they shouldn't have a large problem here.
NM and IA both do this
Degree of Automation
Semi
Processor
Editor
Super Editor
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Approval obtained **and**

Have non-consolidated RCA's **and**
No random sample **or**

Have non-consolidated RCA's **with or without**
Approval not required or SS responsible (for obtaining approvals)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

3.5 Create and Send SS Information

ID: 3.5

Description

This should be very similar to creating an extract of these data groups for the needed data items by process 12.0. Data groups (health record info, patient set, supplemental record info) and special study criteria are needed. Some registries then verify the file against the criteria to make sure selection parameters were correct. This could be actually viewing the records or running frequencies on the selected records. (preventing human error in selection set-up)
Includes checking for controlling Special Studies for all the Patient sets and Health records being sent to the special study if the current special study being processed wants to contact patients.
Also includes the transfer of information to the Special study group.
Retain date sent to study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Special Study Manager
Special Study Staff
IT Staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Outgoing electronic data should be encrypted. Care should be taken in the transfer of paper data to ensure that it is secure.

Trigger

Approval obtained **and**
No matching or consolidation required **and**
No random sample required **or**

Approval not required or SS Responsible **and**
No matching or consolidation required **and**
No random sample required **or**

Matching & consolidation complete

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

3.6 Evaluate Special Study Communication

ID: 3.6

Description

Determine what special study sent - data or request. If data, is registry interested in data item, do they trust the source? If so, consolidate. If request, can registry answer it or is follow-back needed. Basically a traffic cop.

After evaluation of what was received and if registry cares, direct information/request to appropriate process.

Note: most of these notes were taken during a conference call with a few of the registry staff on October 24, 2001. This process involves evaluating the information to determine what could be used to make updates. They may identify follow-up patient information, follow-back patient information, special study contact information, and the need for follow-back, whether the patient has been contacted, the contact date and if the patient is never to be contacted again.

It also includes sending information or requests for information (follow-back) to the appropriate place

In IA and NM, they desire the best information available in a dynamic database…details about treatment, follow up date, date of birth -- anything that would help in routine data management. Include the record of the source of the information, e.g. Special Study.

Timing is an issue here. If the information comes from a Special Study, the patient set information should not be changed until the Special Study is complete. For example, changing an individual (patient) to American Indian status.

This applies to finding new information as well as different information. For example, the race is different. One is not just replacing unknown values with known values; one could also change the data. For things like DOB, someone would need to evaluate and determine which to use.

Opportunities exist when examining this data to discover new cancer/tumor/cases, the need for new abstracts and/or follow-back.

The registries are currently tracking what happens to every patient in a Special Study. So even though in the primary database they are unmarking patients that weren't used, they are using a separate database to track how many times sent etc.

Would like to know which special studies used a particular patient set, the type of contact used; the date of last contact; and if the patient is never to be contacted again.

Check follow-back responses received with this process name in disposition to use in this process.

If follow-back is required, a health record update may be generated here to attach the follow-back response to the health record used by the special study.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries do not want to add special study data to their patient sets because they feel is makes the data quality unbalanced. Not every patient set is included in a special study, so only those included would get this benefit.

In some registries, patients are available to be contacted one year after date of last contact for special studies. In others, patient is interviewed only once ever.

Degree of Automation
Manual
Processor
Special Study Manager
Location
Central Registry Office
Policies/Business Rules
Registries feel that they are in better position to assess 'stage of cancer' than most Special Studies, so it is rare that that would be one of the fields to change.
When a patient has died by the time of the Special Study, some use proxies; some drop them from the study.
Some registries want to know date of physician contact; some get it from the Special Study, if they need it.
Sensitivity

Trigger
Special study communication received
(Follow-Back Complete)
Metrics
Frequency: HI: only 1 or 2 studies return data, would like to increase
Frequency: LA: not many do this, but LA would only use follow-up info anyway.
Volume:
Duration:
Quality/Error rate:

3.7 Modify Special Study Contract

ID: 3.7
Description
Changing information stored about the special study contract, modifying the contract. These changes may be requested by the special study. Reason for change should be noted.
Interested Registries
Interested:
Not Interested:
Local Procedures
HI, IA, NM are interested in capturing an audit log of this.
Degree of Automation
Semi
Processor
Special Study Manager
Registry Manager
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Modification requested
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.8 Check for Shared Participants

ID: 3.8

Description

If the registry allows patients to be involved in multiple studies at the same time, the studies must coordinate to reduce the burden on the patient.

First: When a Special Study notifies the registry that they will be using a patient, the registry checks the IDs of patients sent to other studies to see if any are in use in multiple studies.

Second: If a patient was sent to multiple studies, the 2nd through Nth study are checked to see if they are active studies and if patient contact was requested.

Third: If a patient is found to be included in Special Study A and was sent to other active, contacting studies, all studies involved are notified that the patient is be used by multiple studies and the controlling study is Special Study A.

Interested Registries

Interested:

Not Interested:

Local Procedures

Seattle mentioned this, other registries noted that they also have this need. Seattle is currently only noting that the same path report has been provided to multiple studies, not the same patient or even the same CTC (which may have arrived on multiple paths.)

LA: would give the patient to only one study and would tell others to coordinate if they wish to use the patient. (they would send any information).

IA: Some studies would reject patients involved in other studies.

Degree of Automation

Semi

Processor

Special Studies Manager

Special Studies Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Special study inclusion indicators received

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

3.8.1 Compare Included IDs

ID: 3.8.1

Description

The check to see if a patient has been included in 2 or more active, contacting studies.

First: When a Special Study notifies the registry that they will be using a patient, the registry checks the IDs of patients sent to other studies to see if any are in use in multiple studies.

Second: If a patient was sent to multiple studies, the 2nd through Nth study are checked to see if they are active studies and if patient contact was requested.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Special Studies Manager
Special Studies Staff
Location
CRO
Policies/Business Rules
Given that a patient is included in Special Study A (who wishes to contact them)
Check for Patient/HRec/CTC possibly reportable to Special Study (not A) – That is, has this patient, in any other incarnation, been sent to another special study?
If so, is this study still ongoing (one would hope, if not they should have already sent the patients included back to the registry)?
If so, is patient contact expected for this n^{th} study?
If so, has notification been sent about coordinating for this patient, to these studies?
Sensitivity

Trigger
Special study inclusion indicators received
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.8.2 Notify Special Studies Coordination Needed

ID: 3.8.2
Description
After determining that a patient (via health record, patient set or CTC within a patient set) is being used by multiple special studies, all involved studies are notified that the patient is involved in multiple studies and that all studies should coordinate with the special study that first notified the registry that the patient was included.
Best method is probably a form letter with list of affected IDs and contact information for the controlling Special Study.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Special Studies Manager
Special Studies Staff
Location
CRO
Policies/Business Rules

Sensitivity

Trigger
ID used in multiple active, contacting studies

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

3.8.3 Update Inclusion Tracking

ID: 3.8.3

Description
Retain information about the controlling study for a particular patient within the Registry database. If that patient is included in yet another study after the determination that coordination is needed, the new special study can be directed to the controlling study immediately.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor

Location
CRO

Policies/Business Rules

Sensitivity

Trigger
ID used in multiple active, contacting studies

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.0 Match and Consolidate Patient Set

ID: 4.0

Description
Again, HI recommends NM as good current system.

Match:

This process “matches” one data group with other data groups. These data group are usually patient set information, but can also be person information (supplemental) being matched to patient information.
For PASSIVE FUP: IA is deterministic. NM is probabilistic.
For GENERAL matching: NM probabilistic. IA ordered deterministic, but would like to be probabilistic.
Need name or name and type of cancer to attempt match. (This might not be enough for very common names and cancer/tumors) Matches for childhood CTCs can be done with zip code, dx code and age/dob, however they are manually intensive.
“Match” means search the universe of data groups and find those that might refer to the same patient as the one in the initiating data group.

Data groups include Patient sets Acceptable supplemental info, Acceptable health info, Incomplete Patient Set Info, Non-reportable CTC info, Acceptable Correction/FUP Info, Existing unmatched correction/FUP info, Existing non-reportable health info.
During this process, might determine that something marked as Non-reportable is actually reportable. 1) Correction record matches to non-rpt, changes information relevant to screening. The 2 records together need to be re-screened for reportability. 2) Record comes in (rpt or non) which matches to non-rpt, as information is reviewed, it is determined that the combination of information is reportable – may be incorrect or imprecise info on the non-rpt record. 3) Non-rpt matches to patient set, as info is reviewed, it is determined that the combination of information is reportable with respect to the non-rpt record. Same reasoning as 2, but the modifying information was received prior to the non-rpt and has already been turned into a patient set.
Rules are embedded in the process.
The following decision table helps summarize different possibilities and the corresponding conditions and actions:

Conditions:	Patient Match?	Facility Match?	CTC Match?	Treatment Match?	Different data value?	Type of Information coming in
1	N	(N)	(N)	(N)	N/A	Health rec.
2	N	(N)	(N)	(--)	N/A	Health rec.
3	N	(--)	(N)	(--)	N/A	Dth cert (rpt)
4	N	(N)	(--)	(--)	N/A	Correction (on hold)
5	Y	N	N	(N)	N/A	Health rec.
6	Y	Y	N	(N)	N/A	Health rec.
7	Y	--	N	(N)	N/A	Non-facility record
8	Y	N	N	(--)	N/A	Health rec.
9	Y	Y	N	(--)	N/A	Health rec.
10	Y	--	N	(--)	N/A	Dth cert (rpt)
11	Y	N	Y	N	N/A	Health rec.
12	Y	Y	Y	N	N/A	Health rec.
13	Y	--	Y	N	N/A	Non-facility record
14	Y	N	Y	Y	N/A	Health rec.
15	Y	Y	Y	Y	Y	Correction rec.
16	Y	Y	Y	Y	N	Duplicate
17	Y	N	Y	--	N/A	Health rec.
18	Y	Y	Y	--	Y	Correction rec.
19	Y	Y	Y	--	N	Duplicate
20	Y	--	Y	--	N/A	Dth cert (rpt)
21	Y	N	--	--	N/A	Correction (on hold)
22	Y	Y	--	--	Y	Correction rec.
23	Y	Y	--	--	N	Duplicate
24	Y	--	--	--	N/A	Supplemental rec.

Y: Yes, N: No, N/A: not applicable, --: no information in this category.
(x): this is implied

Actions:	Patient	CTC	Treatment
1	Afac, Areg	Afac, Areg	Afac, Areg
2	Afac, Areg	Afac, Areg	,
3	(Afac), Areg	(Afac), Areg	,
4*	*Create abstraction*	*facility lead, hold*	*correction record*
5	Afac, Creg	Afac, Areg	Afac, Areg
6	Cfac, Creg	Afac, Areg	Afac, Areg
7	, Creg	, Areg	, Areg

8	Afac, Creg	Afac, Areg	,
9	Cfac, Creg	Afac, Areg	,
10	(Afac), Creg	(Afac), Areg	,
11	Afac, Creg	Afac, Creg	Afac, Areg
12#	Cfac, Creg	Cfac, Creg	Afac, Areg
13	, Creg	, Creg	, Areg
14	Afac, Creg	Afac, Creg	Afac, Creg
15	Cfac, Creg	Cfac, Creg	Cfac, Creg
16@	*Send notification:*	*This is a duplicate*	*record*
17	Afac, Creg	Afac, Creg	,
18	Cfac, Creg	Cfac, Creg	,
19@	*Send notification:*	*This is a duplicate*	*record*
20	, Creg	, Creg	,
21*	*Create abstraction*	*facility lead, hold*	*correction record*
22	Cfac, Creg	,	,
23@	*Send notification:*	*This is a duplicate*	*record*
24	, Creg	,	,

C: consolidate, A: Auto create new info;
fac: facility view, reg: registry view. ' ': no information to finalize/create or consolidate in this cell for this view, (Afac): optional to the registry.
*Correction record to a record which hasn't arrived yet, put on hold
@Duplicate facility record, send dup notification to facility.
#Some registries may wish to notify the facility about this as a duplicate, asking them to please send as correction records.

See Match and Consolidate Patient Set.doc in this same directory for more information. A condense version is given below:

IF "Patient Match Status" = 'No', THEN auto create new facility Patient Set and new registry Patient Set, THEN STOP.
IF "Patient Match Status" = 'Yes', and facility view desired THEN do Search for Facility Match.
- IF "Facility Match Status" = 'No', THEN auto create facility patient info.
- IF "Facility Match Status" = 'Yes', THEN consolidate facility patient info.

THEN consolidate registry patient info
IF CTC info exists, THEN do Search for CTC Match.
- IF "CTC Match Status" = 'No' THEN auto create facility CTC set (CTC and treatment), auto create registry CTC set, THEN STOP
- IF "CTC Match Status" = 'Yes'
  - IF "Facility Match Status" = 'No', THEN auto create facility CTC info.
  - IF "Facility Match Status" = 'Yes', THEN consolidate facility CTC info.
- THEN consolidate registry CTC info

IF treatment info exists, THEN do Search for Treatment Match.
- IF "Treatment Match Status" = 'No' THEN auto create facility treatment info, auto create registry treatment set, THEN STOP
- IF "Treatment Match Status" = 'Yes'
  - IF "Facility Match Status" = 'No', THEN auto create facility treatment info.

IF "Facility Match Status" = 'Yes', THEN consolidate facility treatment info.

THEN consolidate registry treatment info, THEN STOP

Consolidate:

This process includes the act of creating a patient set based on a single source as well as merging information from multiple sources into a cohesive whole (consolidation).

If facility information matches, need to consolidate patient set info at facility view first. If no facility match was found, then a new facility set info is added. After the facility information is dealt with (or if no facility match was expected, information from a supplemental record), the registry view can be consolidated.

If treatment info exists, it must be handled (created or consolidated) before CTC consolidation can be completed.

While rare, it could be possible that this process may not result in any updated information. In the case of a duplicate discovered, then a duplicate record notification is sent to originating organization or facility. Duplicate record might get removed (merged with prior copy) at the discretion of the registry.

In some cases, a correction received from a facility may be rejected by the registry. In these cases, the facility is notified and a reason may be provided.

At any point in this process, it can be aborted (for example, because of too many inconsistencies in the data) and return to the Select process. They would like to have all possible matches available for inspection again. From here, they may chose to create new patient set info rather than select another possible.

NOTE: depending on the source of a record, the registry may not choose to create a facility view. For example, a registry may choose to bypass facility view creation if the source record is a death certificate. On the other hand, they may also choose to create a facility view for this source for their own convenience.

Consolidation incorporates the same activities as visual editing. 18.0 is separate because they want to be able to visually edit without doing matching a consolidation.

Design Consideration

MATCH:

When searching for match for correction information, would search facility views (facility match) for facility accession number (patient), and possibly facility sequence number (CTC match) then verify that information on correction record really refers to the same patient/CTC. This puts the facility match first, something not implied by model.

Consider how to best match. Starting at registry view will be 'best' data, if x% match can then check facility view for exact match. Starting at facility view will be more likely to find exact match first if one exists, but would have more views to search through. Consider allowing them to prioritize views: registry first, facility first, facility xxx only (especially important for correction records). If possible and efficient to use all information in the patient set, should probably do that.

Registries expressed concern over amount of automation possible. It sounded like all levels of matching (patient, CTC…) could have probabilistic matching with humans selecting and validating a particular match. They did not seem interested in having a computer decide what matched absolutely. The matching for follow-up purposes seemed to be the exception.

All registries need to have this functionality when electronic records are involved (batch processing). Most registries also need to have a window application where a registry org rep at a facility can enter selected data items to search for patient/CTC/etc in the registry database. The people calling such an app would not necessarily be Editors. Case Finders and Follow-Up clerks may match to supplemental records during the course of their normal work.

Would like to be able to match any 'incoming' data group to all other data groups (i.e. new incomplete patient info matched against all other patient sets, regardless of flags, against all supplemental records and against non-reportable CTC records during the same run.) Rules about possible matches vs accepted matches may change by data source.

Need to have the ability to set parameters for each Match process run. Some matches (such as abstracts) apply very conservative match algorithms. Others (such as supplemental data for FUP) are more relaxed as far as what constitutes an acceptable match. Would potentially be based on data items included, type of record, facility or org source of record (based on their track record of providing quality data).

Discussed package match program. Ron Darling from NM: downsides include that packages are usually pc based, there are too many false positives, packages are expensive ($10K+), are generally record to record, not across multiple files, vendors may not implement needed changes quickly enough. Upsides are vendor maintains it and vendors are experts so it should be sophisticated. Could be investigated more completely.

All registries have different matching algorithms; there might be an opportunity to standardize to best practice(s).

CONSOLIDATE:

Registry will wish to be able to print patient set info in an abstract layout. However, Patient set concept is replacing the 'abstract record'.

Even though HIPAA does not require registries to segregate facility data, we wish to retain the facility view concept, but allow the registry IT staff to disable data items in the facility views. This freedom does not exist for non-reportable diseases (such as non-reportable special studies). Therefore, the person creating the patient set needs to be able to specify whether the disease needs full facility view implementation or not (for each 'CTC').

For conversion of codes and selection of keywords (13.3.2 and 13.8.2 tasks) which can not be automated, registries would manually do those tasks while screening as needed. The balance of these tasks would be done during the Consolidate processes or Conduct Abstracting, as appropriate. Information received at the central registry does not have to be structured as an Abstract before being consolidated.

May be able to automate consolidation done for passive follow-up. They only flag differences in gender. Date of last contact & vital status are automatic.

The registries don't really trust the computer. Best bet seems to be have the computer suggest consolidation results (if value X and value Y, computer suggests value Z) but allow registry to overwrite the suggestion. May not be able to suggest result for all situations.

Doing 5.1 Complete Auto Polishing in the Field may be a new opportunity. It depends if this automation is attached to 4.0 Match and Consolidate or remains as part of 5.0 Polish Registry View Patient Set. Other option will work. (4.0 would happen more often, so would have to be fully automated)
This model shows Adds/Changes/Deletes being stored to the Patient Set (Tracking) data store as they are created. It also shows them being deleted by 4.x.4 Reject processes. It may make more sense to have a temporary storage place for all ACDs generated during 4.0 that is saved to permanent storage only at 4.5.3
It would be nice if 1 reason in an ACD could be applied to multiple changes. For example, when consolidating in a path report, reason would potentially be 'path rcvd 3/13/02, st. joes' and said reason could spawn a multitude of changes. Possibly a history of reason with the latest showing (like CVS's log message box?)
Because 4.2.2/4.2.3 and 4.3.2/4.3.3 and 4.4.2/4.4.3 are so similar, the design team needs to spend time determining ways to streamline the user's effort. They don't want to have to type everything in twice. 1 suggestion would be to allow registries to select fields that would always be carried over into the registry view. Another would be to have a hot key that allows them to note that the change just made to the facility view should also be made to registry view.
Judy Boone in LA would like to have the Fac view consolidated (and visually edited) completely before Reg view is touched. We should consider supporting both. Underlying code could be reusable, but interfaces would be different. If this could be configurable, that would allow managers to change their minds about process order.
Need to be able to see scanned images of source records in addition to the stored data stream 'HREC'.
If matching is done in a batch and held until staff can review/consolidate, the staff need to be able to prioritize the resulting 'to do' list as far as which matches should be resolved first. Examples of priorities would be breast cancer cases; most recent dx date; HRECs from certain facilities; other specified primary sites. This isn't a permanent item and could probably be handled by a standard report ordering the matches to be resolved. Such a report would need to be called before starting 4.2.1
Within this process, they restrict who can do this process and also what kind of changes can be made. For example, only select people can change vital status from dead to alive or back date a date of last contact value.
Need to allow the registry to configure which types of health records they want to consolidate when first received at the registry. For example, Seattle does not consolidation Path reports (autopsy, cytology, hematology, oncology would probably be similar), disease index, or Radiotherapy reports.
Seattle uses Casefinding source information to update unknown data item values, but it's a last resort. Otherwise, would not 'consolidate' this information into the Patient set, as it is not the most reliable.

Record Type Specific Process Notes

Follow-Up Abstracts

If these don't match on CTC, want to create an abstract facility lead.

If these don't match on facility, it will depend on the registry/facility what they want to do. If the FUP abstract just contains additional treatment info, they need to create an abstract facility lead. (If the facility in question does not normal submit FUP abstracts to other facilities, definitely create the lead) If the FUP abstract is for the 2nd use (multiple facilities w/in an org), then only create a lead if no other facilities in the org have submitted a regular abstract.

Follow-Up Record (also Correction Record. Follow-up and correction records have much the same path through the processes.)

1. Follow-up record information (and correction record information) goes directly to 4.0 Match and Consolidate Patient Information since there is not usually information to screen. Search for Patient match. If NO match is found, the information is saved as an unmatched follow-up record (or unmatched correction record) and an abstract facility lead is created.
2. If a patient match is found and there is CTC information on the follow-up record (recurrence or treatment or so on), Search for CTC match. If a CTC match is not found, create an abstract facility lead and save as unmatched follow-up (or unmatched correction record).
3. If a patient match and a CTC match are found and there is treatment information on the follow-up record, Search for Treatment match. Proceed with Search for Facility match (step 4), add treatment information to the patient set. (May be new treatment, so not a big deal if no match is found.)
4. If a patient match is found, Search for Facility match. If none is found, the information is saved as an unmatched follow-up record, an abstract facility lead is created, consolidation of the follow-up information and the registry view patient information may occur at this point. (All is same for correction record.)
5. If a facility match is found, consolidate the facility view, then consolidate the registry view. Unless otherwise determined in step 3, no abstract facility lead should be created.
6. Existing Unmatched follow-up record information is pulled into the matching process when new records arrive so that they may be matched as soon as possible. If they do not match to any of the new records, they remain as unmatched records. If a match is found, it would be nice to remove the abstract facility lead that goes with the follow-up record – probably a maintenance process.

Path Report (where path rpt information goes after 15.0 varies by results)

General path through processes: 13.0 receive record, 1.0 screen record (path), 4.0 match and consolidate.

If no facility match is found or a match is found but no abstract exists: 2.0 generate abstract, 1.0 screen record (abstract), 4.0 match and consolidate (abstract)

Death Certificates:

Death list/index is obtained by the registry. It is scanned for passive follow-up (patient match is found). If true then a death certificate may be requested from the state.

DC is screened for CTC. If found, match DC. If no patient/CTC match exists, DC must be obtained. Some registries would obtain all reportable DCs.
The DC is obtained. If follow-up only, it is merged with patient set, processing is complete. If the DC info was determined to be a new CTC, the DC is screened to verify that it really is a CTC and is then added as an incomplete patient set (or CTC set if patient match exists.) In the case, follow-back is needed.
NOTE: DCs do not need to be matched on facility or treatment as they do not have this information. However, registry may choose to create a facility view.
NOTE: Death list/index (etc) may be matched to database multiple times to verify that additional patients haven't entered the database after 1st match who are listed on the death file. (These records would have been in process when death file received.)

Death Index/Death List, Disease Index, Discharge List, Surgery Log: if reportable and unmatched, these go directly to Conduct Abstracting 2.0, via abstract facility leads (implementation). They do NOT become patient sets by themselves.
Oncology, Radiology, Autopsy, Cytology, Hematology rpts: similar to path reports. When no match is found, they become patient sets and initiate the Conduct Abstracting 2.0 process via abstract facility leads.
NJ: Taxation records – these records (like most supplemental records) are usually processed automatically. However, if the record says 'deceased', it is processed by hand and someone must figure out which person has died (especially for couples filing taxes).

Local Procedures

NCCC: keeps match history: what matched to, decision made, who made decision, etc. Later could do QC tracking on the program or the individual mismatching.
IA: While creating abstract at the facility, the abstractor matches against a copy of the facility view; when abstract reaches the central registry, it is matched against the entire database.
ATL: does matching in the field to a limited extent. Wants to match as completely as possible, as early as possible. Provides all data to field abstractor (not just for that facility)
Check for duplicates as consolidate. Currently, DT rechecks for duplicates every two weeks (to catch matches you should have caught the first time). NM does it once a month.
NCCC: does CTC re-sequencing during consolidation tasks. (4.5.2?)
SEA: does coding during consolidation tasks. Also, do not consolidate path reports when they are first received. Believe the matches are not reliable, so would hold off until a related abstract can be obtained.

Degree of Automation

Fully
Semi

Processor

Editor/Consolidator/Coder
Super Editor
Computerized

The following may initiate Auto Search for…Match
Case finder/screener
Follow-Up staff (Patient Match only)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

The following health records can become patient sets: Abstract, Autopsy Report, Cytology Report, Death Certificate/State Death file record (IA has enough information on short death record to build patient set, other registries must get full DC), Follow-up Abstract, Hematology Report, Indian Health Services Record, Oncology Report, Path Report, Radiology Report, Radiotherapy Report, Special Study record (must have match)
The following health records become abstract facility leads (don't have enough information for patient set): Correction Record, Disease Index, Follow-up Record, Hospital Discharge File, National Death Index, Surgery Log. They are may be stored in Health and Supplemental data until the next match. If a patient match is found, that information should be retained. Some consolidation may be possible.
Obituaries are used for follow-up only

Matching Criteria
Resolution Criteria
SEER & Local Consolidation Rules, such as SEER Rules for multiple primary determination.

Sensitivity

Trigger

Acceptable supplemental info arrived **or**
Acceptable health info arrived **or**
Looking for patient **or**
Information not in patient set (from 10.10.2 to 4.2.2, 4.3.2 or 4.4.2)
Duplicate facility match, not byte for byte (from 13.4.1 to 4.2.1)
Non-FUP patient set info received (from 7.0 to 4.2.2)

Metrics

Frequency:
Match Volume: LA: 50,000 abs per year, 20,000 paths. Currently in DB, 1,000,000 abstracts total, 800,000 patients, 900,000 CTCs. Don't have supplemental count, they only match once and don't retain these online. However, pop counts list population of California at about 33 million.
Match Volume: HI: 8000 records per year, 124,000 patients in DB; probably 1 million supplemental records
Match Volume: NJ: 110,000-120,000 health records; 40,000 follow-up records; 800,000 DMV; 130,000 tax records; about 3000 CMS.
Consolidate Volume: LA: 50 per day
Consolidate Volume: HI: 500+ per month
Match Duration: HI: 100 CTCs probably 5-10 minutes. 1 CTC about 15 seconds.
Match Duration: LA: overnight batch job, no idea how long. 1 CTC about 30 seconds.
Consolidation Duration: HI: they do about 6 CTCs an hour, (takes about 10 minutes); however, this is from input into system through consolidation complete. For HI, this estimate does not include text consolidation.
Consolidation Duration: LA: they do about 50 CTCs a day; again, this is from input into system through consolidation complete.
Quality/Error rate:
Consolidation: Volume: NJ: about 1/3 of data flow into registry needs to be consolidated.

4.1 Automated Match and Build Information

ID: 4.1

Description

All the automatic tasks included in matching and consolidation. Includes Searching for Match at the Patient, Facility, CTC and Treatment levels, automatically creating new sets of information when no match is found, and the creation of abstract facility leads when needed. Since this is just the entire automated part, the various sub-processes may be somewhat disconnected. It includes 8 Logical Business Transactions. See each sub-process for more detail.

DESIGN NOTE: If incoming record is DC or Path report and no matches have been found, the automated creation part should fill in data items that aren't expected to be available on the document with the registry default values. If a data item value is found, org rep needs to be able to over write the default with the correct value.

Interested Registries

Interested:
Not Interested:

Local Procedures

Seattle does this as part of casefinding, but does not move on to consolidation. They only make AFLs (4.1.2) from here during casefinding.

Degree of Automation

Fully

Processor

The following may initiate the entire process:
Editor/Consolidator/Coder

The following may initiate Auto Search for…Match:
Case finder/screener
Follow-Up staff (Patient Match only)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Acceptable supplemental info arrived **or**
Acceptable health info arrived **or**
Looking for patient **or**
Apparent duplicate patient matches rejected **or**
Abstract needed based on non-reportable health records **or**
All possible patient matches rejected **or**
Possible patient match rejected, no more possibles exist **or**
All possible CTC matches rejected **or**
Possible CTC match rejected, no more possible exist **or**
Other facility referenced **or**
Passed reportable screen **or**
CTC selection made, no facility match **or**
Treatment selection made, no facility match **or**
All possible treatment matches rejected **or**
Possible treatment match rejected, no more possibles exist **or**
Patient matched, patient consolidation complete, CTC info exists **or**
CTC matched, CTC consolidation complete, Treatment info exists
(Composite CTC data items will not be completed at this point)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.1 Search for Patient Match

ID: 4.1.1

Description

Comparing patient information found in incomplete patient set info, non-reportable CTC info, acceptable correction/FUP info, supplemental info, existing unmatched correction/FUP info, existing non-reportable health info and the existing patient sets to determine whether this patient is already a part of the database.
Match Incomplete Patient Set Info against existing patient sets or existing non-reportable health info or existing unmatched correction records/FUP info or supplemental records.
OR
Match Non-reportable CTC Info OR Acceptable Correction/FUP Info OR Supplemental Record against existing patient sets or existing non-reportable health info or existing unmatched correction records/FUP info or supplemental records.
OR
Match existing Patient Set to existing Patient Set.
OR
Match non-reportable health record to non-reportable health record OR unmatched correction record.
When matching, one or more 'matching to' data groups could be a possible match to the data group being matched. (Match A to B: A could match to B1, B2, B3)
From any of the acceptable health records, once 'match' is found, then 'update (consolidate) follow-up' information can occur. (same with Supplemental, but these records aren't being used for anything else but consolidation purposes).
Input data flows for unmatched correction records and follow-up records are here because they might arrive before the patient set is added.
Correction record, supplemental record, active follow-up record and non-reportable health record may come in after patient set established.
Children have been matched by zip code, dx code and age/dob, but it is manually intensive.
Generally need Name. Ideally would have name, dob and SSN. Zip code is nice to have, but not essential.
Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.

DESIGN NOTE: They seem to be doing this in multiple passes with different matching rules currently. For example, pass 1 might be blocked on SSN and matched on last name, first name, DOB; pass 2 would be blocked on SSN and matched on Soundex of last name, first name, sex, dob; pass 3 would be blocked on DOB (month and year) and matched on sex, last name, first name and SSN. This allows for time efficient matching without missing people for blocking variable problems.
DESIGN NOTE: in probabilistic matches, weights may be based on error rates and frequency. Error rate – how often the data item is mis-keyed or otherwise incorrect. High error rates (such as are found with SSN) would imply that a mismatch on that item is not as serious. Frequency –

how often a particular value of the data item occurs in the data. A match on a more frequency item (Smith as opposed to Tarentino) would be less important.

Interested Registries

Interested:

Not Interested:

Local Procedures

NM makes list of patient sets who are alive and 'haven't heard from date' has been too long. Sends Registry Patient ID, SSN and other information? to HCFA. Not sure what Ron gets back, but the data runs through 13.0 and then through 4.1.1 (analogous to expedited passive follow-up). **If no match in 4.1.1, then something is wrong and follow-back is initiated.**

NCCC, LA, ATL – there is a manual review of all system proposed matches before a final decision is made – they want to continue this. Other registries accept a system proposed exact match. We want to allow weight variances for matching per Registry.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

For follow-up records and correction records, if a match is not found, processing is discontinued and the record is retained for future processing. Should create an abstract facility lead. This is also true for list type health records, however processing may continue for these depending on registry policy.

All registries have similar, but different algorithms for determining a patient match. One option would be to get the Registries to agree to common matching elements but allow them to place different weights on the items.

Supplemental records and follow up records (and death certificates used as passive follow-up) only need to be matched at the patient level.

Implementation note: when matches not found, this could be just a status change on the record or could be an update to "match identifying information' or could be other mechanisms as yet unidentified.

DESIGN NOTE: it is not known yet how often the patient and CTC match routines will need to be changed; and it seems like that would be a SEER-wide decision. So the frequency and responsiveness requirements may not be the same as the 'Search for Facility Match' changes.

Sensitivity

Trigger

Acceptable supplemental info arrived **or**

Acceptable health info arrived **or**

Looking for patient **or**

Apparent duplicate patient matches rejected

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

4.1.2 Create Abstract Facility Lead

ID: 4.1.2

Description

Using a facility id, the patient and CTC identifying information, create an abstract facility lead for future use.

This may be caused by a facility reference with no corresponding facility view.

This may also be caused by a correction, follow-up or list type health record that fails to match at the patient, CTC and facility level.

DESIGN NOTE: may need to note if a lead is a physician office only type record as it may not be possible to get an abstract until the patient has been through the hospital system.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Abstract needed based on non-reportable health records **or**
All possible patient matches rejected **or**
Possible patient match rejected, no more possibles exist **or**
All possible CTC matches rejected **or**
Possible CTC match rejected, no more possible exist **or**
Other facility referenced **or**
No Patient match for health->lead info **or**
No CTC match found for health->lead **or**
No facility match for health->lead info

Metrics

Frequency:

Volume: LA: doesn't do this. HI: Would love to do this, not automated now, so doesn't have numbers.

Duration:

Quality/Error rate:

4.1.3 Auto Build Patient Facility View

ID: 4.1.3

Description

If no patient match or no facility match were found, the computer can automatically fill in most of the patient set data items using information found in the incoming data.

Some data items may need human review (consolidation of patient) after this has occurred. However, a large portion of the work could be done here.

The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility

has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

No patient match for reportable health **or**
Passed reportable screen **or**
Patient match, no facility match **or**
All possible patient matches rejected **or**
Possible patient match rejected, no more possibles exist

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.4 Auto Build Patient Registry View

ID: 4.1.4

Description

If no patient match was found, the computer can automatically fill in most of the patient set data items using information found in the incoming data.

Some data items may need human review (consolidation of patient) after this has occurred. However, a large portion of the work could be done here.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

No patient match, Fac Patient done

Metrics

Frequency: LA: about 38000 patients per year added. Probably only 37000 from LA.
Frequency: HI: most of the 5500 processes CTCs per year are new.
Volume:
Duration:
Quality/Error rate:

4.1.5 Auto Build CTC Facility View

ID: 4.1.5

Description

If no CTC match or no facility match were found, the computer can automatically fill in most of the patient set data items using information found in the incoming data.
Some data items may need human review (consolidation of CTC) after this has occurred. However, a large portion of the work could be done here.
The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

No patient match, Pat done, CTC info available **or**
No CTC match **or**
CTC match found, no facility match exists **or**
All possible CTC matches rejected **or**
Possible CTC match rejected, no more possibles exist **or**
CTC selection made, no facility match

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.6 Auto Build CTC Registry View

ID: 4.1.6

Description

If no CTC match was found, the computer can automatically fill in most of the patient set data items using information found in the incoming data.

Some data items may need human review (consolidation of CTC) after this has occurred. However, a large portion of the work could be done here.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

(No patient OR No CTC) match, Fac CTC done

Metrics

LA: about 42000 CTCs per year added
Volume:
Duration:
Quality/Error rate:

4.1.7 Auto Build Treatment Facility View

ID: 4.1.7

Description

If no treatment match or no facility match were found, the computer can automatically fill in most of the patient set data items using information found in the incoming data.
Some data items may need human review (consolidation of tx) after this has occurred. However, a large portion of the work could be done here.
The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

(No patient OR No CTC) match, CTC done, Tx info available **or**
No treatment match **or**
Treatment match found, no facility match exists **or**
Treatment selection made, no facility match **or**
All possible patient matches rejected **or**
Possible treatment match rejected, no more possibles exist

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.8 Auto Build Treatment Registry View

ID: 4.1.8

Description

If no treatment match was found, the computer can automatically fill in most of the patient set data items using information found in the incoming data.
Some data items may need human review (consolidation of tx) after this has occurred. However, a large portion of the work could be done here.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

(No patient OR No CTC OR No Tx) match, Fac Tx done

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.9 Search for Facility Match

ID: 4.1.9

Description

Comparing facility information found in incomplete patient set info, non-reportable CTC info, acceptable correction/FUP info, existing unmatched correction/FUP info, or existing non-reportable health info against the patient matched existing patient set to determine whether this facility is already a part of that Patient Set. I.e. is there a facility view for this facility?
'Search for Facility Match' may not be performed for 'Death Certificates' since they are do not have facilities. However, some registries express interest in having a facility view for this record type.
Need Facility ID. May need a crosswalk file from Facility calls itself to what the registry calls the facility, but that's implementation.

The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change.
DESIGN NOTE: if possible, would be nice to allow facility match to happen pre or post Patient matching. Registry may wish to select which facility views to search, in other words, to search for facility match first. This is especially true for correction records. This implies not all incoming data flows are needed, although all could be used if they are available.
DESIGN NOTE: allow registries to determine what information gets a 'facility view' – all health information definitely does, but will probably be useful to have patient information supplemental record views. This allows DMV info to be kept separate if legally necessary.
Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
DESIGN NOTE: may want to allow IT to determine if this happens immediately post Search for Patient Match or immediately pre Search for Treatment Match when they determine what information they are including in the facility view. If they exclude all Patient and CTC information, it would not make sense to do this before the Patient and CTC information has been dealt with.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM, DT - For follow-up record type, if a match is not found, processing is discontinued and the abstract is retained for future processing. The processing of this is similar to correction records. See Follow-Up Record in BOM text for more information.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

For correction records, if a match is not found, processing is discontinued and the record is retained for future processing. Create abstract facility leads in this case.
Supplemental records are not usually matched at this level.
Implementation note: when matches not found, this could be just a status change on the record or could be an update to "match identifying information' or could be other mechanisms as yet unidentified.
DESIGN NOTE: allow the registries to be able to modify the criteria here very easily. If facilities start being bought and sold and id numbers start changing, they are going to have to be able to take care of that quickly themselves.
If Patient match and Facility match are found, may be able to update patient information on the facility view. If CTC information was also present, would have to create a new CTC in the patient set as well.

Sensitivity

Trigger

Patient match found, facility view desired **or**
Selection made, facility view desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.10 Search for CTC Match

ID: 4.1.10

Description

Comparing CTC information found in incomplete patient set info, non-reportable CTC info, acceptable correction/FUP info, existing unmatched correction/FUP info, or existing non-reportable health info against the patient matched existing patient set to determine whether this CTC is already a part of that Patient Set.

Need to consider if the recurrence field has changed. If everything else matches except the recurrence field, you need to create a new primary.

If there is no match at CTC level, then considered a new CTC for existing patient.

Need Site, Hist, Date of Dx. Typically resolve close CTCs using text description during consolidation. Very hard to automate past the general site code & time window match/don't match. A lot of human intervention is typical when disease and timing are similar.

Update 'Match Identifying Info'.

Check follow-back responses received with this process name in disposition to use in this process.

Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM, DT - For follow-up record types, if a match is not found, processing is discontinued and the abstract is retained for future processing. The processing of this is similar to correction records. See Follow-Up Record in BOM text for more information.

NCCC, LA, ATL – there is a manual review of all system proposed matches before a final decision is made – they want to continue this. Other registries accept a system proposed exact match. We want to allow weight variances for matching per Registry.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

SEER Rules exist for how to match a CTC.

For correction records, if a match is not found, processing is discontinued and the record is retained for future processing. Should create an abstract facility lead. (This is a generalization of the NM, DT procedures for follow-up abstracts). This is also true for list type health records, however processing may continue for these depending on registry policy.

Implementation note: when matches not found, this could be just a status change on the record or could be an update to "match identifying information' or could be other mechanisms as yet unidentified.
Follow-up records and supplemental records are not usually matched at this level (because they don't have this sort of information).
DESIGN NOTE: it is not known yet how often the patient and CTC match routines will need to be changed; and it seems like that would be a SEER-wide decision. So the frequency and responsiveness requirements may not be the same as the 'Search for Facility Match' changes.

Sensitivity

Trigger

Patient match found for 2 non-rpt records **or**
Patient matched, patient consolidation complete, CTC info exists

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.1.11 Search for Treatment Match

ID: 4.1.11

Description

Comparing treatment information found in incomplete patient set info, non-reportable CTC info, acceptable correction/FUP info, existing unmatched correction/FUP info, or existing non-reportable health info against the CTC matched existing patient set to determine whether this treatment is already a part of that Patient Set. Probably based on major type of treatment (surg, chemo, etc).
While some registries keep separate line items for each date of event (such as CT), this process should probably only support match by major type and leave more exact matching to the registry staff if needed.

If Patient and CTC and Facility matches, but Treatment does not, then is considered new treatment for existing Patient and CTC and Facility. (some registries would call this a facility correction or facility duplicate.)
'Search for Treatment Match' is not performed for Death Certificates as they do not have treatment information. Need type (surgery, chemo) and date. Other records may not have treatment info either (path rpt might not, etc)
Registries aren't currently doing this as a separate process. They are consolidating treatment and part of that is deciding if information about a treatment refers to the same or different event.
Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

CT and DT use same system. They save individual treatment information; they save all treatment that comes in. Most of this is done by people, not by computers. Other registries aren't really doing treatment match. (Mentally done within consolidation)
NCCC, LA, ATL – there is a manual review of all system proposed matches before a final decision is made – they want to continue this.

Other registries accept a system proposed exact match. We want to allow weight variances for matching per Registry.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

For correction records, match not found at this level may imply that the correction is the addition of the treatment.
Implementation note: when matches not found, this could be just a status change on the record or could be an update to "match identifying information' or could be other mechanisms as yet unidentified.
Follow-up records and supplemental records are not usually matched at this level (because they don't have this sort of information).

Sensitivity

Trigger

CTC matched, CTC consolidation complete, treatment info exists (Composite CTC data items will not be completed at this point)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.2 Resolve Possible Patient Match & Consolidate Patient Info

ID: 4.2

Description

Selecting a patient match if only possible matches have been found
Consolidating patient information for the facility and registry view
If a possible patient match was selected and is found to be too inconsistent during the actual consolidation process, the match can be rejected and a new match selected.
Final decision on whether the patients match doesn't just depend on patient identifying information (i.e. name, SSN); could use CTC information, etc. Could be anything in the patient set to make the patient match decision. The rejection of match would flow up from treatment to CTC to patient.
Non-reportable records could be discovered during this process. The incomplete patient set information being examined could be determined at this point to be non-reportable even after it has passed the screening process earlier.

Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
Editing occurs here

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Registries would like to have all possible matches available for viewing while doing the selection. After selecting an appropriate match, they would start consolidating, but may need to abort consolidation and return here – in that case, they would again want all possible matches available.
Supplementary data may be used (ex: MVD, Voter's Registration, etc.) to help resolve the possible matches

Sensitivity

Trigger

Possible patient match found **or**
Duplicate facility match, not byte for byte (from 13.4.1) **or**
Patient match, Facility match found **or**
Patient match found, no facility view needed **or**
Patient match, no Facility match, Auto Fac patient done **or**
Composite patient data items needed **or**
Non-FUP patient set info received (from 7.0) **or**
Information not in patient set (from 10.10.2) **or**
Want to reject selected patient match

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.1 Select Possible Patient Match

ID: 4.2.1

Description

Given that there are 1 or more possible patient matches, all possibles are displayed and the processor selects one.
If a selected match has been rejected, the system returns here to select another match.

Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.

Interested Registries

Interested:
Not Interested:

Local Procedures

Seattle does some of this during casefinding. They are trying to determine if they need a abstract or if they already have information.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Registries want all potential matches available for review.

Sensitivity

Trigger

Possible patient match found **or**
Duplicate facility match, not byte for byte (from 13.4.1) **or**
Possible patient match rejected, more possibles exist

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.2 Consolidate Patient Info Facility View

ID: 4.2.2

Description

This involves comparing the Patient Information in the facility view to the matched data, identifying inconsistencies, and then determining the best value for each data item (ex: date of birth, race, …).

DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.

The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change.

Determine 'DCO' indicator.

In the odd case that 2 death certificates have been received for the same person, manual review of information on the DCs and follow-back with the Vital Statistics Bureau are combined to determine best information. Both DCs are kept. (This would happen if both the physician and the Office of Medical Investigators filled out a DC).

If data value doesn't match (when compared), then may wish to retrieve the other records (health and supplemental) to determine the best value.

Summary data for Patient across CTCs and facilities is established here.

If there are too many inconsistencies and it is determined that an incorrect Patient Match has been made, this process will be aborted via '4.2.4 Reject Patient Match'.

If we change patient information that is match criteria, then we will need to re-match to look for additional matches. Could be done immediately or after consolidation is complete.

Want to have previous history of data item values available for consideration in case values don't match. (Adds/Change/Delete)

May decide that consolidated information reveals the patient is not reportable. Would save and note non-reportable reason and status at this point.

If correction is rejected when consolidating facility view, registry may choose to notify data source that correction was rejected and why via '4.7 Facility Notification'.

Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
For each data item to be evaluated until all are complete:
Compare values for Data Item
Determine Best Value for Consolidation
Edit Patient Set Info Compare Values to Rules (field edit, cross-field edit and inter-CTC edit)
Determine whether to continue (considering all items reviewed thus far)

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Editor/Consolidator/Coder
Super Editor

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules
SEER Rules
Local Rules
Need to track who does this

Sensitivity

Trigger
Patient match, Facility match found **or**
Patient match found, no facility view needed **or**
Patient match, no Facility match, Auto Fac patient done **or**
Composite patient data items needed **or**
Non-FUP patient set info received (from 7.0) **or**
Information not in patient set (from 10.10.2) **or**
Selection made, no facility view needed

NOTE: Composite should also include data items which need to be created based on text (something the computer may not be able to do)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.2.1 Compare Values for Patient Data Item

ID: 4.2.2.1

Description
Look at the values of the patient information data item (SSN, Name, DOB) on the existing patient set and the matching data to determine if they are equal or different.
If new data item value and the existing data item value match, Update 'Comparison Results Information', Evaluate to Continue, Compare Next Item. **DESIGN NOTE**: This should all be computerized.
If there is no match, then 'Determine Best Value for Patient Consolidation' (**DESIGN NOTE**: allow manual intervention here), then

Update 'Comparison Results Information', Evaluate to Continue, Compare Next Item.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

(4.2.2 only: Facility match found)
Patient match found, consolidation needed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.2.2 Determine Best Value for Patient Consolidation

ID: 4.2.2.2

Description

Determine the best value when two values for a data item do not match. Result may be the existing value, the incoming value, or a completely new value.
If correction is rejected when consolidating facility view, registry may choose to notify data source that correction was rejected and why.
In some cases, the result may be to mark the patient set as non-reportable.
Some of the coding that occurs here is more that just what has been defined in 13.3.2 and 13.8.2. May need to convert text to codes; compare the values and then select the best value.

This uses the history of adds/changes/deletes because sometimes the existing value might be different from the new value, but the new value is the same as historical value(s).
Need to update data item tracking for any changes that are made.
Refer to the following table for possible value results:

#	Scenario	Incoming Value	Existing Patient Set Value	Other Value	Data Item Match?	Possible Results(s)
1.	Two matching values	X	X		Yes	X (wouldn't be here)
2.	Two blank/ unknown values	(blank/ unknown)	(blank/ unknown)		Yes	(blank/unknown) (wouldn't be here)
3.	Only one value	Y	(blank/ unknown)		No	Y (blank/unknown)
4.	Only one value	(blank/	Y		No	(blank/unknown)

		unknown)				Y
5.	Two values	X	Y		No	X Y A
6.	More than two values	X	Y	Z	No	X Y Z A

If a totally new value is chosen, registry may wish to send updated data back to the Data Source (if there are changes beyond the correction) via 14.0, Update Data Source.
This triggers 17.0 Edit Patient Set Info after each change. A failed inter-field edit should not halt the process.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM, CT, UT – Don't compare many of the values when existing patient set is a death certificate or path-only is what is in the Patient Set.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

SEER Rules
Local Rules
Good Judgment
Note: This is an opportunity for automating the rules as much as possible or to make suggestions.

Sensitivity

Trigger

Data Item Values Don't Match
(Edit Complete)
(Follow-back Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.2.3 Evaluate to Continue Patient Consolidation

ID: 4.2.2.3

Description

Reviewing 'comparison results' and possibly other criteria, deciding whether to continue consolidation or to abort and select another match
This could be done before 'Determine Best Value for Patient Consolidation' or after depending on criteria used to make decision.
Ideally, a weighted ratio of number items matched / number items checked. May be more important that last name doesn't match than the day of birth doesn't match. Types of mis-match may also matter.

Missing data not matched to valid value less important than 2 inconsistent valid values. 'Typo' type errors are less important than others (Jonh vs John as opposed to John vs James).
Also, evaluate whether newly changed value makes this patient non-reportable. If so, change status and save reason.
DESIGN NOTE: May be able to provide computer messages warning of high inconsistencies. However, this will be a human's decision.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Verification of possible match desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.3 Consolidate Patient Info Registry View

ID: 4.2.3

Description

This involves comparing the Patient information over all the facility views for the matched data, identifying any inconsistencies, and then determining the best value for each data item (ex: date of birth, race, …). Determine 'DCO' indicator.
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.
In the odd case that 2 death certificates have been received for the same person, manual review of information on the DCs and follow-back with the Vital Statistics Bureau are combined to determine best information. Both DCs are kept. (This would happen if both the physician and the Office of Medical Investigators filled out a DC).
If data value doesn't match (when compared), then may wish to retrieve the other records (health and supplemental) to determine the best value.
Summary data for Patient across CTCs and facilities is established here.
If there are too many inconsistencies and it is determined that an incorrect Patient Match has been made, this process will be aborted via '4.2.4 Reject Patient Match'.
If we change patient information that is match criteria, then we will need to re-match to look for additional matches. Could be done immediately or after consolidation is complete.

Want to have previous history of data item values available for consideration in case values don't match. (Adds/Change/Delete)
May decide that consolidated information reveals the patient is not reportable. Would save and note non-reportable reason and status at this point.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
For each data item to be evaluated until all are complete:
Compare values for Data Item
Determine Best Value for Consolidation
Edit Patient Set Info Compare Values to Rules (field edit, cross-field edit and inter-tumor edit)
Determine whether to continue (considering all items reviewed thus far)

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Editor/Consolidator/Coder
Super Editor

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules
SEER Rules
Local Rules
Need to track who does this

Sensitivity

Trigger
Composite patient data items needed, fac patient done **or**
Patient matched, fac patient done

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.2.4 Reject Patient Match

ID: 4.2.4

Description
If the evaluation of whether to continue patient consolidation fails, the patient match needs to be rejected. All consolidation for patient up to that point would be undone.
The status on the Match Entity for patient would be set to Rejected.
If other possible patient matches are available, this exits into '4.2.1 Select Possible Patient Match'. Otherwise, it exits into '4.1.3 Auto Create Patient Facility View'.

Interested Registries
Interested:
Not Interested:

Local Procedures

LA: should have selected correct CTC before this point, therefore few rejections.

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Patient match rejected **or**
Want to reject selected patient match

Metrics

Frequency: LA: Rare HI: Rare
Volume:
Duration:
Quality/Error rate:

4.3 Resolve Possible CTC Match & Consolidate CTC Info

ID: 4.3

Description

Selecting a CTC match if only possible matches have been found
Consolidating CTC information for the facility and registry view
If a possible CTC match was selected and is found to be too inconsistent during the actual consolidation process, the match can be rejected and a new match selected.
Non-reportable records could be discovered during this process. The incomplete patient set information being examined could be determined at this point to be non-reportable even after it has passed the screening process earlier.

Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
Editing occurs here

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Registries would like to have all possible matches available for viewing while doing the selection. After selecting an appropriate match, they

would start consolidating, but may need to abort consolidation and return here – in that case, they would again want all possible matches available.

Sensitivity

Trigger

Possible CTC match **or**
CTC match found, facility match exists **or**
Information not in patient set (from 10.10.2) **or**
CTC match, no facility match, auto fac CTC done **or**
Composite CTC data items needed, no treatment info **or**
Treatment consolidation complete, Composite CTC data items needed **or**
Want to reject selected CTC match

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.1 Select Possible CTC Match

ID: 4.3.1

Description

Given that there are 1 or more possible CTC matches, all possibles are displayed and the processor selects one.
If a selected match has been rejected, the system returns here to select another match.

Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.

Interested Registries

Interested:
Not Interested:

Local Procedures

Seattle does some of this during casefinding. They are trying to determine if they need a abstract or if they already have information.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Registries want all potential matches available for review.

Sensitivity

Trigger

Possible CTC match **or**
Possible CTC match rejected, more possibles exist

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.2 Consolidate CTC Info Facility View

ID: 4.3.2

Description

This involves comparing the CTC Information in the facility view to the matched data, identifying inconsistencies, and then determining the best value for each data item (ex: site, date of diagnosis, histology, …).
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.
The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change.
If there are too many inconsistencies and it is determined that an incorrect CTC Match has been made, this process will be aborted via '4.3.4 Reject CTC Match'.
Want to have previous history of data item values available for consideration in case values don't match. (Adds/Change/Delete)
May decide that consolidated information reveals the CTC is not reportable. Would save and note non-reportable reason and status at this point.
Medical coding may be occurring here and in Consolidate Treatment Information if it has not occurred during Convert ICD Codes & Decipher Disease Text or Create Abstract.
If there are too few differences here and no treatment information, may decide that this is effectively a duplicate record to something already received by the registry. Would notify the facility that duplicates have been sent and could they please stop.
If duplicate CTC information or duplicate record is determined, an explanation of the duplicate will be sent to originating organization or facility via '4.7 Facility Notification'.
If correction is rejected when consolidating facility view, registry may choose to notify data source that correction was rejected and why via '4.7 Facility Notification'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
For each data item to be evaluated until all are complete:

- Compare values for Data Item
- Determine Best Value for Consolidation
- Compare Values to Rules (field edit, cross-field edit and inter-tumor edit)
- Determine whether to continue (considering all items reviewed thus far)

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. However, we need to allow them to type in the response (possibly with auto complete) as some believe this is faster.

If variables which affect the stage of disease have different values in the incoming record than the patient set (or may be better to check to see if a variable which affects stage changes during consolidation), we may wish to post a message to verify stage.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

SEER Rules
Local Rules

Sensitivity

Trigger

CTC match found, facility match exists **or**
CTC selection made, facility match exists **or**
Information not in patient set (from 10.10.2) **or**
CTC match, no facility match, auto fac CTC done **or**
Composite CTC data items needed, no treatment info **or**
Treatment consolidation complete, Composite CTC data items needed **or**

NOTE: Composite should also include data items which need to be created based on text (something the computer may not be able to do)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.2.1 Compare Values for CTC Data Item

ID: 4.3.2.1

Description

Look at the values of the CTC information data item (Date of DX, site, histology, behavior) on the existing patient set and the matching data to determine if they are equal or different.
If new data item value and the existing data item value match, Update 'Comparison Results Information', Evaluate to Continue, Compare Next Item. **DESIGN NOTE**: This should all be computerized.
If there is no match, then 'Determine Best Value for CTC Consolidation' (**DESIGN NOTE**: allow manual intervention here), Update 'Comparison Results Information', Evaluate to Continue, Compare Next Item.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

CTC match found, consolidation needed
(4.3.2 only: **and** Facility match found)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.2.2 Determine Best Value for CTC Consolidation

ID: 4.3.2.2

Description

Determine the best value when two values for a data item do not match. Result may be the existing value, the incoming value, or a completely new value.
If correction is rejected when consolidating facility view, registry may choose to notify data source that correction was rejected and why.
In some cases, the result may be to mark the CTC set (and possibly the patient set) as non-reportable.
Some of the coding that occurs here is more that just what has been defined in 13.3.2 and 13.8.2. May need to convert text to codes; compare the values and then select the best value.

This uses the history of adds/changes/deletes because sometimes the existing value might be different from the new value, but the new value is the same as historical value(s).
Need to update data item tracking for any changes that are made.
Refer to the following table for possible value results:

#	Scenario	Incoming Value	Existing Patient Set Value	Other Value	Data Item Match?	Possible Results(s)
1.	Two matching values	X	X		Yes	X (wouldn't be here)
2.	Two blank/ unknown values	(blank/ unknown)	(blank/ unknown)		Yes	(blank/unknown) (wouldn't be here)
3.	Only one value	Y	(blank/ unknown)		No	Y (blank/unknown)
4.	Only one value	(blank/ unknown)	Y		No	(blank/unknown) Y
5.	Two values	X	Y		No	X Y A
6.	More than two values	X	Y	Z	No	X Y Z A

If a totally new value is chosen, registry may wish to send updated data back to the Data Source (if there are changes beyond the correction) via 14.0, Update Data Source.
This triggers 17.0 Edit Patient Set Info after each change. A failed inter-field edit should not halt the process.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM, CT, UT – Don't compare many of the values when a death certificate or path-only is what is in the Patient Set.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

SEER Rules
Local Rules
Good Judgment
Note: This is an opportunity for automating the rules as much as possible or to make suggestions

Sensitivity

Trigger

Data Item Values Don't Match
(Edit Complete)
(Follow-back Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.2.3 Evaluate to Continue CTC Consolidation

ID: 4.3.2.3

Description

Reviewing 'comparison results' and possibly other criteria, deciding whether to continue consolidation or to abort and select another match
This could be done before 'Determine Best Value for CTC Consolidation' or after depending on criteria used to make decision.
Ideally, a weighted ratio of number items matched / number items checked. May be more important that histology doesn't match than the 4 digit of the site code doesn't match. Types of mis-match may also matter. Missing data not matched to valid value less important than 2 inconsistent valid values. Typo type errors less important than others (1 node vs 2 nodes as opposed to 1 node vs 5 nodes)
Also, evaluate whether newly changed value makes this CTC non-reportable. If so, change status and save reason.
DESIGN NOTE: May be able to provide computer messages warning of high inconsistencies. However, this will be a human's decision.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Editor/Consolidator/Coder
Super Editor
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Verification of possible match desired
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.3 Consolidate CTC Info Registry View

ID: 4.3.3
Description
This involves comparing the CTC information over all the facility views for the matched data, identifying any inconsistencies, and then determining the best value for each data item (ex: site, date of diagnosis, histology, …).
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.
Summary data for CTC (including Treatment) across facilities is established here.
If there are too many inconsistencies and it is determined that an incorrect CTC Match has been made, this process will be aborted via '4.3.4 Reject CTC Match'.
Want to have previous history of data item values available for consideration in case values don't match. (Adds/Change/Delete)
May decide that consolidated information reveals the CTC is not reportable. Would save and note non-reportable reason and status at this point.
Medical coding may be occurring here and in Consolidate Treatment Information if it has not occurred during Convert ICD Codes & Decipher Disease Text or Create Abstract.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
For each data item to be evaluated until all are complete:
Compare values for Data Item
Determine Best Value for Consolidation
Compare Values to Rules (field edit, cross-field edit and inter-tumor edit)

Determine whether to continue (considering all items reviewed thus far)

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. However, we need to allow them to type in the response (possibly with auto complete) as some believe this is faster.

Interested Registries

Interested:
Not Interested:

Local Procedures

NCCC – does CTC re-sequencing here.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

SEER Rules
Local Rules

Sensitivity

Trigger

Composite CTC data items needed, fac CTC done **or**
CTC matched, fac CTC done

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.3.4 Reject CTC Match

ID: 4.3.4

Description

If the evaluation of whether to continue CTC consolidation fails, the CTC match needs to be rejected. All consolidation for CTC up to that point would be undone.
The status on the Match Entity for CTC would be set to Rejected.
This rejection may also cause the need to reject the patient match.
If patient match is kept and if other possible CTC matches are available, this exits into '4.3.1 Select Possible CTC Match'. Otherwise, it exits into '4.1.5 Auto Create CTC Facility View'.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

CTC match rejected **or**
Want to reject selected CTC match

Metrics

Frequency: HI: this is somewhat visual editing, somewhat consolidation; more frequent rejection of CTC match than patient match.
Volume:
Duration:
Quality/Error rate:

4.4 Resolve Possible Treatment Match & Consolidate Treatment Info

ID: 4.4

Description

Selecting a treatment match if only possible matches have been found
Consolidating treatment information for the facility and registry view
If a possible treatment match was selected and is found to be too inconsistent during the actual consolidation process, the match can be rejected and a new match selected.

Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
Editing occurs here

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Possible treatment match **or**
Treatment match found, facility match exists **or**
Information not in patient set (from 10.10.2) **or**
Treatment match, no Facility match, auto fac tx done
Composite treatment data items needed **or**

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

4.4.1 Select Possible Treatment Match

ID: 4.4.1

Description

Given that there are 1 or more possible treatment matches, all possibles are displayed and the processor selects one.
If a selected match has been rejected, the system returns here to select another match.

Update 'Match Identifying Info'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Registries want all potential matches available for review.

Sensitivity

Trigger

Possible treatment match **or**
Possible treatment match rejected, more possibles exist

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.4.2 Consolidate Treatment Info Facility View

ID: 4.4.2

Description

This involves comparing the Treatment Information in the facility view to the matched data, identifying inconsistencies, and then determining the best value for each data item (ex: surgery date, type of procedure, type of radiation, …).
DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.
The view of the patient set from the facility view is not what the facility does with the patient, but what the facility knows about the patient even if some treatments have occurred at other facilities. It is what the facility

has told the registry. It does not include corrections the registry would like the facility to make until the facility confirms the change
If there are too many inconsistencies and it is determined that an incorrect Treatment Match has been made, this process will be aborted via '4.4.4 Reject Treatment Match'.
(There is no treatment information to consolidate for a death certificate.)
Want to have previous history of data item values available for consideration in case values don't match. (Adds/Change/Delete)
Medical coding may be occurring here and in Consolidate CTC Information if it has not occurred during Convert ICD Codes & Decipher Disease Text or Create Abstract.
If there are too few differences, may decide that this is effectively a duplicate record to something already received by the registry. Would notify the facility that duplicates have been sent and could they please stop.
If duplicate treatment information or duplicate record is determined, an explanation of the duplicate will be sent to originating organization or facility via '4.7 Facility Notification'.
If correction is rejected when consolidating facility view, registry may choose to notify data source that correction was rejected and why via '4.7 Facility Notification'.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
For each data item to be evaluated until all are complete:
Compare values for Data Item
Determine Best Value for Consolidation
Compare Values to Rules (field edit, cross-field edit and inter-tumor edit)
Determine whether to continue (considering all items reviewed thus far)

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. However, we need to allow them to type in the response (possibly with auto complete) as some believe this is faster.
If variables which affect the stage of disease have different values in the incoming record than the patient set (or may be better to check to see if a variable which affects stage changes during consolidation), we may wish to post a message to verify stage.
For duplicate records, the computer should be doing most of the 'consolidating' as very few differences will be found. It should only be interacting with the org rep when a difference is found.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

SEER Rules
Local Rules

Sensitivity

Trigger

Treatment match found, facility match exists **or**
Treatment selection made, facility match exists **or**
Information not in patient set (from 10.10.2) **or**
Treatment match, no Facility match, auto fac tx done **or**
Composite treatment data items needed **or**

NOTE: Composite should also include data items which need to be created based on text (something the computer may not be able to do)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.4.2.1 Compare Values for Treatment Data Item

ID: 4.4.2.1

Description

Look at the values of the treatment information data item (Date, Kind, performing physician) on the existing patient set and the matching data to determine if they are equal or different.
If new data item value and the existing data item value match, Update 'Comparison Results Information', Evaluate to Continue, Compare Next Item. **DESIGN NOTE**: This should all be computerized.
If there is no match, then 'Determine Best Value for Treatment Consolidation' (**DESIGN NOTE**: allow manual intervention here), Update 'Comparison Results Information', Evaluate to Continue, Compare Next Item.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Treatment match found, consolidation needed **or**
(4.4.2 only: **and** Facility match found)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.4.2.2 Determine Best Value for Treatment Consolidation

ID: 4.4.2.2

Description

Determine the best value when two values for a data item do not match. Result may be the existing value, the incoming value, or a completely new value.

If correction is rejected when consolidating facility view, registry may choose to notify data source that correction was rejected and why.

Some of the coding that occurs here is more than just what has been defined in 13.3.2 and 13.8.2. May need to convert text to codes; compare the values and then select the best value.

This uses the history of adds/changes/deletes because sometimes the existing value might be different from the new value, but the new value is the same as historical value(s).

Need to update data item tracking for any changes that are made.

Refer to the following table for possible value results:

#	Scenario	Incoming Value	Existing Patient Set Value	Other Value	Data Item Match?	Possible Results(s)
1.	Two matching values	X	X		Yes	X (wouldn't be here)
2.	Two blank/ unknown values	(blank/ unknown)	(blank/ unknown)		Yes	(blank/unknown) (wouldn't be here)
3.	Only one value	Y	(blank/ unknown)		No	Y (blank/unknown)
4.	Only one value	(blank/ unknown)	Y		No	(blank/unknown) Y
5.	Two values	X	Y		No	X Y A
6.	More than two values	X	Y	Z	No	X Y Z A

If a totally new value is chosen, registry may wish to send updated data back to the Data Source (if there are changes beyond the correction) via 14.0, Update Data Source.

This triggers 17.0 Edit Patient Set Info after each change. A failed inter-field edit should not halt the process.

Check follow-back responses received with this process name in disposition to use in this process.

Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:

Not Interested:

Local Procedures

NM, CT, UT – Don't compare many of the values when a path-only is what is in the Patient Set.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder

Super Editor

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

SEER Rules
Local Rules
Good Judgment
Note: This is an opportunity for automating the rules as much as possible or to make suggestions.

Sensitivity

Trigger
Data Item Values Don't Match
(Edit complete)
(Follow-back Complete)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.4.2.3 Evaluate to Continue Treatment Consolidation

ID: 4.4.2.3

Description
Reviewing 'comparison results' and possibly other criteria, deciding whether to continue consolidation or to abort and select another match This could be done before 'Determine Best Value for Treatment Consolidation' or after depending on criteria used to make decision. Ideally, a weighted ratio of number items matched / number items checked. May be more important that radiation type doesn't match than the day of treatment doesn't match. Types of mismatch may also matter. Missing data not matched to valid value less important than 2 inconsistent valid values. Typo type errors less important than others (1 vs 2 as opposed to 1 vs 9 where 9=unknown/missing)
DESIGN NOTE: May be able to provide computer messages warning of high inconsistencies. However, this will be a human's decision.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Editor/Consolidator/Coder
Super Editor

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger
Verification of possible match desired

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.4.3 Consolidate Treatment Info Registry View

ID: 4.4.3

Description

This involves comparing the Treatment Information over all the facility views for the matched data, identifying inconsistencies, and then determining the best value for each data item (ex: surgery date, type of procedure, type of radiation, …).

DESIGN NOTE: They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.

Summary data for Treatment across facilities is established here.

If there are too many inconsistencies and it is determined that an incorrect Treatment Match has been made, this process will be aborted via '4.4.4 Reject Treatment Match'.

(There is no treatment information to consolidate for a death certificate.)

Want to have previous history of data item values available for consideration in case values don't match. (Adds/Change/Delete)

Medical coding may be occurring here and in Consolidate CTC Information if it has not occurred during Convert ICD Codes & Decipher Disease Text or Create Abstract.

Check follow-back responses received with this process name in disposition to use in this process.

Dynamically create and submit follow-back request as needed.

For each data item to be evaluated until all are complete:

- Compare values for Data Item
- Determine Best Value for Consolidation
- Compare Values to Rules (field edit, cross-field edit and inter-tumor edit)
- Determine whether to continue (considering all items reviewed thus far)

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. However, we need to allow them to type in the response (possibly with auto complete) as some believe this is faster.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder

Super Editor

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

SEER Rules

Local Rules

Sensitivity

Trigger

Composite Tx data items needed, fac tx done **or**
Treatment matched, fac tx done
(fac=facility, tx=treatment)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.4.4 Reject Treatment Match

ID: 4.4.4

Description

If the evaluation of whether to continue treatment consolidation fails, the treatment match needs to be rejected. All consolidation for treatment up to that point would be undone.
The status on the Match Entity for treatment would be set to Rejected.
This shouldn't happen – treatment is not currently being matched by exact day, merely by type.
This rejection may also cause the need to reject the CTC match.
If CTC match is kept and if other possible treatment matches are available, this exits into '4.4.1 Select Possible Treatment Match'.
Otherwise, it exits into '4.1.7 Auto Create Treatment Facility View'.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Treatment match rejected

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.5 Finalize Consolidation

ID: 4.5

Description

This process is used to indicate that the collection of data about a patient is available for use but is not ready for submission to SEER.
This shows that the information is no longer a 'work-in-progress' (or incomplete) and may be used in some reports, etc.
Patient set and CTC set IDs are assigned during this step.
DESIGN NOTE: May wish to initiate '18.3 Conduct Patient Set-to-Patient Set Matching' at the end of this task to see if any data that has changed brings to light a duplicate patient set. i.e. if SSN has changed during consolidation, matching may reveal that 2 sets should be combined.

DESIGN NOTE: May wish to initiate '18.4 Assess Likelihood Treatment Complete' at the end of this task to see if any abstract facility leads need to be created because of missing treatment.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Consolidation complete to level of information (includes Patient consolidation complete, no CTC info; CTC consolidation complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.5.1 Incorporate All Info into Single Patient Set & Review

ID: 4.5.1

Description

After all processing of the separate types of information (patient, CTC and treatment) is completed, it must be incorporated into a single patient set. Depending of the system design, this may have occurred as consolidation and auto create were happening.

Once all data is tied together, the patient set can be reviewed before being saved. This would include a final check of all edits, a check that all facilities mentioned have views or abstract facility leads and so on.

The review is mostly manual, but the data will be displayed in some kind of screen.

Check follow-back responses received with this process name in disposition to use in this process.

Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Patient consolidation complete, no CTC info **or**
CTC consolidation complete

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

4.5.2 Assign IDs

ID: 4.5.2

Description

After the patient set has been consolidated and any new information has been incorporated, a registry ID can be assigned to the PATIENT or to the CTCs as needed. In some cases, the patient and CTC will already have IDs and nothing happens within this task.

This is a NP placement for this task. At this point in the process, the patient and CTC are cohesive wholes, there shouldn't be duplication. Therefore, there will not be gaps or duplicates in the IDs assigned. Since health records have IDs (and are linked to the patient set), there shouldn't be any problems tracking information because of this placement.
DESIGN NOTE: if there is a way to assign a temporary ID to a patient set that was formed from a non-abstract record, it may need to be a design consideration. Concern is that a partial patient set of this type might not match to an existing patient set. When the abstract comes in, the data would obviously match to the partial patient set, but the match to the existing patient set could then be found because information was more complete. Arguing against this, at submission time, if this is still a partial patient set, the registry would want to make it a 'real' ID and submit it.

Interested Registries

Interested:
Not Interested:

Local Procedures

The registries currently do this task at a variety of places. They all agree that IDs should not be reused and gaps must be accounted for. Their current assigning methods do not lend themselves well to this.
LA, HI currently assign registry ID here. They assign a temporary id to facility flow through the system up to this point.
DT: record is received and matched, assigned an ID and placed in the suspense file. (if matched, get matching ID, else gets new ID). This will probably be okay for them.

Degree of Automation

Fully

Processor

Computerized
(Initiated by Editor/Consolidator/Coder or Super Editor)

Location

Central registry
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger
Patient Set Processing Completed
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.5.3 Establish Patient Set as Consolidated

ID: 4.5.3
Description
After the patient set has been fully consolidated, all new information has been incorporated, any new IDs needed have been assigned, and editing has been completed, the patient set can be considered Consolidated.
This is a status setting. It implies that the patient can be polished and then submitted. If no new information is received, editing should not be needed after this point.
DESIGN NOTE: May want to allow the ability to print the patient set as an abstract here as well, since this would be the 'final' version.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Editor/Consolidator/Coder
Super Editor
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
IDs Assigned
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

4.6 Screen Non-Reportable Records Match

ID: 4.6
Description
When matching a non-reportable record, if a match is found, these data groups must be re-screened collectively.
Sometimes information on the 2 records together is found to be reportable, usually when information changes (ie the address is now in the registry catchment area, the histology of the CTC has been modified).

May wish to review non-reportable reasons during this process to see what prevented the reportable status so can focus attention on that data item.

Interested Registries

Interested:
Not Interested:

Local Procedures

HI: not likely to find reportable CTC here, most likely gaining follow-up information
LA: does not store non-reportables on DB currently, so this is not an issue.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central registry
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Non-reportable record match found

Metrics

Frequency:
Volume: HI: very low
Duration:
Quality/Error rate:

4.7 Facility Notification

ID: 4.7

Description

If a correction record was sent to the registry and the registry does not agree with the new data value, they reject the correction and notify the facility of that. They may also wish to say why or what data value they do have.

If a duplicate record has been sent (in many registries, this is a record which matched on patient, facility, CTC and possibly treatment), the registry would notify the facility of this. Some facilities send corrections this way, and then the registry would ask the facility to send correction records.

DESIGN NOTE: need to have either a disable key for notifications (possibly by facility) or a review before sending notices.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries consider Patient matched info + CTC matched info + facility matched info + New treatment info type match and Patient matched info + CTC matched info + facility matched info + treatment matched info type match to be duplicates.

Seems likely that they would consider Patient matched info + CTC matched info + facility matched info + No treatment info type match a duplicate as well.

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super Editor

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Correction rejected (from 4.2.2, 4.3.2, 4.4.2) **or**
Duplicate record discovered (from 4.3.2, 4.4.2)

Metrics

Frequency:
Volume: HI: not doing a lot now because it's not automated and they don't want to alienate the hospital. More likely to send value changes than duplication notifications.
Duration:
Quality/Error rate:

5.0 Polish Registry View Patient Set

ID: 5.0

Description

A submissible patient is eligible for submission, analyzing, or incidence reporting per registry rules. It is 'polished' to the best of the registry's knowledge (which may change the next day). Some sub-processes may not be documented here.
The data set is examined to determine if there are any Critical Missing variables. Follow-back should be initiated to acquire this information. See local procedures.
This might happen in the name of cleaning up a patient set for submission to a special study (especially rapid case ascertainment), as well as for the "normal" use of cleaning up for SEER.
NOTE: Need to determine if field and inter-field edits are needed within this process. If field and inter-field edits have been done as the patient set information is being manipulated (in Consolidate), then would not **need** to be done here. However, the registries are probably going to want the ability (They are somewhat paranoid – hard to tell how much is personality and how much is holdover from poor systems.)
NOTE: Death Info: When a DC is received, determined to be a new CTC and during the course of follow-back, there is no source or the trail dead-ends and the registry is unable to obtain additional information, they mark this as a DCO (see glossary) and perform this process.

Interested Registries

Interested:
Not Interested:

Local Procedures

Critical Missing Information will vary by registry. SEER is the core and then other fields by Registry. For example, one registry may be doing a special study and need additional/different information.
Atlanta (CL) determines critical missing information in "13.0 Confirm Receipt of Data" and as bringing things into Health Record Data.
May wish to allow for registry patient id number assignment at this point, although it should be assigned in '4.5.2 Assign IDs'.

Degree of Automation

Processor
Computerized
Editor

Location
Central Registry Office
Field Laptop (freestanding) 5.1

Policies/Business Rules
This is not required for data to be used (Patient Set deemed 'usable'), but these routines would need to be performed for data to be submissible to SEER.
DESIGN NOTE: Currently, is done in batch process – frequently, final batch run is done just prior to SEER submission. If this is automated, may be possible to do in-line. (5.4 Assign Census tract is most likely to remain batched) Would be run on any patient set that had been touched (modified or added) since last batch.

Sensitivity

Trigger
Patient set consolidated **(optional and)**
Submission due

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

5.1 Complete Auto-Polishing

ID: 5.1

Description
DESIGN NOTE: Seems to make the most sense to move this process into 4.5! At very least move 5.1.1 and 5.1.3; there should be no reason why 5.1.2 can't be moved, but 5.1.4 (census tract) may have to stay apart from consolidation.

Before a patient set is submissible, the computer needs to verify that all critical data items are present, the ethnicity and census tract assigned, and possibly reset data items.
Doing this process in the Field may be a new opportunity. It depends if this automation is attached to 4.0 Match and Consolidate or remains as part of 5.0 Polish Registry View Patient Set. Other option will work. (4.0 would happen more often, so would have to be fully automated)

Interested Registries
Interested:
Not Interested:

Local Procedures
LA does this during consolidation, but rechecks it here. (these could be edits) They do some of the calculation type variables on the fly as the extract is created.
HI does this with consolidation.

Degree of Automation
Fully

Processor
Computerized
(NM: Editor for 5.1.2)

Location
Central Registry Office

Field Laptop (freestanding) – new opportunity, if fully automated, can be done with 4.0 tasks

Policies/Business Rules

Sensitivity

Trigger

Patient set consolidated **(optional and)**
Submission due

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.1.1 Determine and Reset Data Items

ID: 5.1.1

Description

DESIGN NOTE: Seems to make the most sense to move this process into 4.5!

NOTE: This happens for lots of data items.
Update data items that depend upon other data items by calculating, resetting, or re-coding data items.

Calculate is defined as: a mathematical procedure (e.g., age of diagnosis, survival time) taking two values and determining another.
Reset is defined as: changing value to "unknown" to force a re-code (e.g., Census Tract when address is changed). NOTE: reasons sound implementation based.
Re-code is defined as: assigning a new code based on comparing against list or table of values (e.g., Site group, race recode, SEER site re-code)

This should also include filling in previous versions of coding schemes (icd-9 and icd-8 from an icd-10 field value)

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding) – new opportunity, if fully automated, can be done with 4.0 tasks

Policies/Business Rules

Sensitivity

Trigger

Patient set consolidated **(optional and)**
Submission due

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.1.2 Assign Ethnicity

ID: 5.1.2

Description

DESIGN NOTE: May make sense to move this process into 4.5!

Takes possible ethnicity from the Surname program and uses patient demographic information (surnames, maiden names, a.k.a., gender, place of birth, marital status, etc.) and list of names to verify or re-code ethnicity/race.
This is a Registry Verification process. This is a computer assigned ethnicity code, for most. See local procedures below.
Note: Automate rules as much as possible.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM, UT – uses GUESS program to return Hispanic, American Indian, white.
Some Registries use the computer-generated code as is. Others (e.g., NM) use it in conjunction with one or more other fields determined by a person (using the computer assigned code as input); in these cases, must store both the 'selected ethnicity code' and the SEER required 'computer derived ethnicity code'.
The Asian list includes names and a code; the Spanish list includes names (returns a yes or no).
While LA and HI check the program during its set up, they don't verify the codes being returned against known patient information.

Degree of Automation

Fully

Processor

Computerized
Editor (NM)

Location

Central Registry Office
Field Laptop (freestanding) – new opportunity, if fully automated, can be done with 4.0 tasks

Policies/Business Rules

SEER requires the "Computer-derived Ethnicity Code" as a variable.
Some registries also use further processing (and possibly intuition) to produce a "better" ethnicity code.
Registries may use different ethnicity standards

Sensitivity

Trigger

Patient set consolidated **(optional and)**
Submission due

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.1.3 Determine if Missing Critical Data Item(s)

ID: 5.1.3

Description

DESIGN NOTE: Seems to make the most sense to move this process into 4.5!

Trying to determine if a patient set is complete. Can have a complete CTC set if all the CTC information and patient information is considered complete (but a 2nd CTC was not).

DESIGN NOTE: a complete patient set would be complete for all uses. To check for completeness, would check outstanding follow-back and critical values. Registry may chose to override a failure of these rules if they believe they are not going to get better information. (path only, dc only.)

Could be considered part of QC (18.0). Involves reviewing the registry view patient set and checking to see if any of the critical data items are missing (see Local Procedures below).

Can't be done until all information has been collected and consolidated so that registry can tell what is missing (as opposed to what's on another record).

Will generate follow-back to obtain missing data item values.

Critical missing implies that the patient set can't be considered truly submissible without this information.

Critical data items include mainly: Residency status (may be based on state and or county), Date of Diagnosis (specifically year), Site, Histology, Behavior, and for some/most registries Date of Birth (again, specifically year)

Interested Registries

Interested:

Not Interested:

Local Procedures

Critical Missing Information will vary by registry. SEER is the core and then other fields by Registry. For example, one registry may be doing a special study and need additional/different information.

Atlanta (CL) determines critical missing information in "13.0 Confirm Receipt of Data" and as bringing things into Health Record Data.

LA: does this as part of editing, a record in this state would not be marked as submissible.

HI: only thinks of path only cases in this scenario because of missing addresses. Wouldn't do this task pre-submission – data item would have to have unknown value.

SEA: If they determining that a casefinding record has a Patient, Facility and CTC match, they do this process to determine if more information should be acquired from the facility. This would lead to 8.0

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Field Laptop (freestanding) – new opportunity, if fully automated, can be done with 4.0 tasks

Policies/Business Rules

Sensitivity

Trigger

Patient set consolidated **(optional and)**

Submission due

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.1.4 Automatically Assign Census Tract

ID: 5.1.4

Description

The computer automatically assigns the census tract code based on address at time of diagnosis (per CTC) and date of diagnosis.
NOTE: The boundaries of census tracts are subject to change every 10 years.
DESIGN NOTE: This is currently done as out-sourced batch. Would be nice to allow the capability for in-line processing (in case information is already in registry). However, there may be manual resource constraints in making the assignment. If it is determined that computer could accommodate the assignment rules, no reason this couldn't be in-line.

Interested Registries

Interested:
Not Interested:

Local Procedures

NCCC, LA - There may be a requirement to obtain more than one census code because the codes change every 10 years.
Some registries periodically send batches of addresses to an outside organization, which assigns a census tract for each.
Some registries (e.g. NM, DT) do the mapping in-house.
Some registries have found that maintaining this was headache producing. They have decided that outsourcing this task (in batch mode) went more smoothly.
LA: submits address information to CA central registry quarterly and gets census information back in about 6 weeks.
HI: tries to do this as the records are loaded. They have in-house look up table.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding) – new opportunity, if fully automated, can be done with 4.0 tasks

Policies/Business Rules

Census tract codes (and boundaries) change every 10 years.
DESIGN NOTE: This process may also be done at other times; not just when finalizing a Patient Set. For example, if the information is available on initial record, it could be called from 13.4 Convert Codes (current policy of batching and outsourcing make this timing unlikely), or it could be done as a background process as address or census tract information becomes available. However, if this involves any significant amount of work for the registry staff, they will want to do it only during the 5.0 process.
Must be able to batch process this.

Sensitivity

Trigger

Patient set consolidated **(optional and)**
Submission due

Metrics

Frequency:
Volume:
Duration: Outsource LA: 6 weeks.
Quality/Error rate: HI: most problems caused by lack of standardized addresses.

5.2 Assign Census Tract

ID: 5.2

Description

Assign census tract code based on address at time of diagnosis (per CTC) and date of diagnosis.
NOTE: The boundaries of census tracts are subject to change every 10 years.
DESIGN NOTE: This is currently done as out-sourced batch. Would be nice to allow the capability for in-line processing (in case information is already in registry). However, there may be manual resource constraints in making the assignment. If it is determined that computer could accommodate the assignment rules, no reason this couldn't be in-line.

Interested Registries

Interested:
Not Interested:

Local Procedures

NCCC, LA - There may be a requirement to obtain more than one census code because the codes change every 10 years.
Some registries periodically send batches of addresses to an outside organization, which assigns a census tract for each.
Some registries (e.g. NM) do the mapping in-house.
Some registries have found that maintaining this was headache producing. They have decided that outsourcing this task (in batch mode) went more smoothly.

Degree of Automation

Semi

Processor

Editor/coder

Location

Central Registry Office

Policies/Business Rules

Census tract codes (and boundaries) change every 10 years.
DESIGN NOTE: While this could be done at other times, since this is a manual task, the registries will most likely continue to do it here.
Must be able to batch process this.

Sensitivity

Trigger

Census tract certainty too low **or**
Could not assign census tract **or**
New address received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.2.1 Evaluate Census Tract

ID: 5.2.1

Description

Check the census tract code produced in "5.1.4 Automatically Assign Census Tract" against the actual address to see if it's reasonable. If the code is plausible, OK. If the code is missing, then it must be due to a problem with the address. Correct the address (may require follow-back), and ask for reassignment.

The census tract code leaving this process is good, i.e. scrubbed. It doesn't need to be edited further.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/coder

Location

Central Registry Office

Policies/Business Rules

Bring in-house.
Note: opportunity for mechanized business rules?
Note: correction to address, whether through follow-back or just a change that an editor makes, needs to be stored in patient set.

Sensitivity

Trigger

Census tract certainty too low

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.2.2 Lookup Census Tract

ID: 5.2.2

Description

If a census tract for a particular address was unable to be assigned automatically, a member of the census tract staff needs lookup the address on the computer.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Editor/coder

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

New census tract needed **or**
Could not assign census tract **or**
New address received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

5.3 Establish Patient Set as Submissible

ID: 5.3

Description

This process is used to indicate that the collection of data about a patient is available for submission.
This allows that the information is no longer just 'consolidated' (or usable), but is now submissible.
17.0 Edit Patient Set Info should be allowed to occur here prior to 'submissible' flag being set. (Field and Inter-field) While this is redundant, it would make the registries happy. See 5.0 text.
May wish to do 18.3 Conduct Patient Set-to-Patient Set Matching (Patient in DB twice under 2 different patient sets, a quality control check) prior to this process.
DESIGN NOTE: Although this is generally thought of in terms of SEER, it may make sense to add submissible flags for all relevant agencies during this process. The registries would have to add this for the most part, as these are probably not consistent across registries.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sometimes, the registry may mark something as submissible for the submission and then wish to mark it as 'unsubmissible'. This wouldn't be driven by changes in data, it is driven by the registry's desire to keep their reporting numbers up. This depends on a judgment call as to whether the things that currently make the data unsubmissible are critical.

Sensitivity

Trigger

Census Tract OK (includes Census tract assigned) **and**
Information Complete (includes No critical missing items, Ethnicity assigned, & Census tract assigned)
(Edit Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

6.0 Acquire Death Certificate

ID: 6.0

Description

Submit request for death certificate when an entry in the death file/index is determined to be needed by the registry. (Needed in NM if 4.1.1 Search for Patient Match succeeds. Needed in all registries if 1.2/1.3 screen for reportability succeeds AND 4.1.1 Search for Patient Match fails or 4.1.10 Search for CTC Match fails.)

PROCESSING OF DEATH INFO: The registry obtains death list/index. It is scanned for passive follow-up (patient match is found) and for new CTCs (passes fine filter for Cancer/Tumor/Case). Death certificate is requested from the state if desired according to local rules.

The DC is obtained. If follow-up only, it is merged with patient set, processing is complete. If this is a new CTC, the DC is screened to verify that it really is a CTC and is then added as an incomplete patient set (or CTC set if patient exists.) In the case, then do Follow-back to gather facility information (and hopefully abstract) for the CTC.

They are shooting for 0.4% DCOs at the end of the submission period.

Most registries only request DC only when index record passed the fine CTC screen and no CTC match is found (or no patient match is found, which implies no CTC match). NM & HI additionally requests DC for all index records where a patient match is found for follow-up.

DESIGN NOTE: These things happen occasionally: (1) One person has two death certificates. (2) Two people have the same DC number. (3) No DC is issued (or at least none gets filed correctly with the government).

DESIGN NOTE: It is important to the registries to know that a PATIENT/CTC started as a DCO and is now something else (physician's office, facility, etc). We currently track if a case is DCO. With the facility view for DC implemented, we would know that the DC facility view was created first (hence started as DCO) and that the PAT/CTC is now a xxx case. However, not all registries will choose to have a separate view for DCs, so we need a back-up to cover this need. This would likely be checking to see if there is a ACD for DCO flag turning it off.

Interested Registries

Interested:

Not Interested:

Local Procedures

For some registries, this may be just printing the DC from a tape (ATL, DT). They would not enter this process at all, as they already have the info.

Some registries send person to Vital Records department, look up DC and scan it in (NM, UT, HI). The DC actually enters the system via 13.0.

Some have to request and pay for copy of DC (LA, SF). The DC actually enters the system via 13.0.

ATL, DT, LA, HI, IA: Only do this for DCO, not FUP

NM: only receive NM and AZ state death certificates.

Degree of Automation

Fully

Semi

Manual

Processor

Computerized

Death Clearance Manager

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

HI & NM: 4.1.1 Search for Patient Match succeeds
All: Death tape w/ CTC, no patient match **or**
All: Death tape w/ CTC, no CTC match
(All - 1.2/1.3 Screening succeeded, 4.1.1 Search for Patient Match or 4.1.10 Search for CTC Match failed).

Metrics

Frequency: LA: yearly- in Dec/Jan
Frequency: HI: monthly review of DC tape, quarterly/semi-annually acquire DC.
Volume: LA: 1400-1500; HI 2000
Duration:
Quality/Error rate:

6.1 Gather List of Needed Death Certificates

ID: 6.1

Description

For all deceased patients, the registry may like to have a copy of their death certificate. For all DCO's, the registry NEEDS a death certificate. The registry gathers a list of all patients that they need a dc for and either send the list to the Vital Statistics Bureau or visits the Vital Statistics Bureau.
If in the future, they can connect directly to the vital statistics system to get what they need, there's no reason not to gather a DC as you need it. (as is done in those registries where they just have to print the full DC from the data media)

Interested Registries

Interested:
Not Interested: DT: their death tape has the full DC on it already, they have no need to do any of these processes.

Local Procedures

DESIGN NOTE: Seattle would like to be able to decide to request the death in cases where they have critical missing items that they believe could be found on the death certificate (DX date, Site, Address).

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

6.2 Go to Vital Statistics Bureau and Acquire Death Certificates

ID: 6.2

Description

Some registries have to physically go to the Vital Statistics Bureau to obtain a DC. They are usually making some sort of copy of the DC there, such as a scanned doc.

Interested Registries

Interested: NJ (there are others)
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Death Clearance Manager
Death Clearance Staff

Location

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Need to acquire death certificates in person

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

6.3 Send List to Vital Statistics Bureau

ID: 6.3

Description

Some registries are able to just send a list of DCs that they need to the Vital Statistics Bureau instead of going there. Some sort of electronic file is returned.

Interested Registries

Interested: LA (there are others)
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Death Clearance Manager
(task is clerical in nature)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Need to request bureau to send death certificates

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

7.0 Conduct Active Follow-Up

ID: 7.0

Description

The process of determining if follow-up information needs to be updated and, if so, obtaining the information. The query and response are tracked.

Ultimate goal is to monitor patient vital status and this is done throughout the life of the patient

The need to send a query is based on the date of last contact and today's date.

The information collected includes follow-up sources, dead or alive, date of last contact, causes of death, CTC status, recurrence, Death Certificate #, current demographics, follow-up contact, etc.

Querying specific individuals, facilities or organizations for information on patients we have already identified.

For example this may include physician and patient letters, phone calls, hospital visits, lost to follow-up listings/CTC registry hospital listings, internet follow-up, data files, etc.

Limited to those patients who were last known to be alive

Expensive because manually intensive

Interested Registries

Interested:

Not Interested:

Local Procedures

Some registries exclude Cervix IN-SITU and benign

There are a lot of local procedures.

LA – has a "shared follow-up" process which involves hospital to registry information. The hospital sends records to the registry which are similar to "correction records," but with somewhat different fields.

NCCC – has a "shared follow-up" process that involves sharing data between hospitals. This is done when hospitals have signed agreements to share data. If hospital A sends information to the registry, the registry can then share that data with hospital B.

HI – is trying to distribute the task of active follow-up among its hospitals. They would then ensure that all hospitals had the follow-up information they needed via 14.0 Update Data Sources.

DT – Every 3 months, create extract of patients who have date of last contact older than 14 mths. Some hospitals do FUP themselves, DT would not do FUP for patients from that hospital alone. These hospitals are supposed to send yearly files with the FUP for their patients. For other patients, lists of patients needing FUP are sent to physician offices. If do not contact physician, can call patient or go to doctor's office as specified by instructions provided by Dr. When forms are returns if AFUP need was not met, they may call patient if Dr. has given ok. DT keeps at least 2 such extract files (current file and file before).

Degree of Automation

Fully

Semi

Manual

Processor

Computerized

Follow-up Clerk

Abstractor (in Field, in role of Follow-up Clerk)

Location

Central Registry Office

Field Laptop (freestanding)

Field Registry Staff Home (logged in)

Policies/Business Rules

Local law may prohibit contacting patients (minors, Native American Indians)
Some hospitals don't let you contact the patients (patient doesn't know, they don't want to hear the patient complain about being contacted)
Do Not Contact flags available and respected for patients and physicians.
Most likely to follow-up with Medical Practitioners, Facilities, Organizations and Org Reps. Some Registries would NEVER follow-up with Patient or Informants. Others would (probably as a last resort) and only by phone.

Sensitivity

For a variety of reasons (mental impairment, children, elderly, prohibited by law, etc.) you don't want to contact the patient, but someone else may serve as contact, ex: legal guardian.
Some patients do not want to be contacted
Some physicians do not want to be contacted

Trigger

Follow-up due (i.e. submission coming) **or**
Periodically

Metrics

Frequency:
Volume: ATL: 2000 letters/year
Duration:
Quality/Error rate:

7.1 Determine Eligibility for Active Follow-Up

ID: 7.1

Description

The computer determines whether a patient requires Active Follow-up based on a Registry's criteria. Does registry need to find a better date for known vital status?
Would be active because passive means (DMV and other large files, checking all incoming health records) have not yielded a better date.
There are SEER and local rules for eligibility. May also be rules determining priority. Some rules (set by registries) should deal with how much time is acceptable between an action and a response before a new action is required.
Seattle's rules for this are complicated – they have a matrix set up to handle these rules.
Lost to follow-up (today's date – date of last contact) is pretty steady
DESIGN NOTE: Need to have different settings for different runs.
DESIGN NOTE: Would also be nice to have the option of getting the work flow to compile and email a weekly list to appropriate staff so the work is more constant.

Interested Registries

Interested:
Not Interested:

Local Procedures

Eligibility requirements could be very different among registries.
LA: year's list first created after Aug submission. In May, those who are about to be lost to follow-up are added.

Degree of Automation

Fully

Processor

Computerized (Initiated by FU Manager)

Location

Central Registry Office

Policies/Business Rules

Basic rules:
Is patient alive?
Is date of last contact prior to XXXX?
Is follow-up necessary for this CTC (in situ cervix is an exception, most do require follow-up)?
Assign priority (under 20 crowd has priority b/c they typically have the worst follow-up rates)

Sensitivity

Trigger

Periodically **or**
Follow-up due (i.e. submission coming)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

7.2 Send Follow-Up Queries

ID: 7.2

Description

After process 7.1 determines who is eligible for active follow-up, the follow-up staff sends out follow-up letters (queries) to the proper facility/organization or calls an appropriate person or visits the facility.

Interested Registries

Interested:
Not Interested:

Local Procedures

IA: uses patients and informants as first, best source of follow-up information.
LA: NEVER contacts patient.
HI: would only use patient if person has lost to follow-up status. They have to obtain physician consent before contacting the patient for this.
DT: can't contact some patients for FUP because facility wants to do so. If facility can't find information or stops tracking, then registry can contact them again. Patients are last resort, facilities and doctors are first.
NM: tries physician, then patient or informant, then facility.

Degree of Automation

Fully
Semi
Manual

Processor

Computerized
Follow-up Clerk

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

If the time is June or July, multiple actions may be occurring simultaneously.

Sensitivity

Trigger

Eligible for active follow-up **or**
Response inadequate (no date or date prior to current FUP) **or**

Need to try a different method (from 10.6.1.1)

Metrics

Frequency: Mostly in May, June and July, but constant during these months
Volume: LA: 6000 (1992-present) HI: 5500 (1973-present) ATL 2000/year (dr. letters)
Duration:
Quality/Error rate:

7.2.1 Determine Type of Active Follow-Up

ID: 7.2.1

Description

Given that we want to do active follow-up for a patient, determine the mechanism for follow-up and with whom.
Must check 'do not contact medical practitioner indicator' and 'do not contact patient indicator'.

On first attempt for cycle, would want to know what follow-up types worked or didn't work in the past.
On 2nd and later attempts, would possibly need info in 1st attempt's response (not my patient, now with dr. so and so) to select type.
DESIGN NOTE: Could argue that this information is added to patient set (7.3->4.0 and7.4) prior to this process being redone (would have to remove Active Follow-up Response inflow and add Patient Set inflow)
DESIGN NOTE: ideal world would be electronic list of FUP needs from registry to hospital, electronic response from hospital. Not all hospitals can handle this.
Seattle's rules for this are complicated and vary by facility – they have a matrix set up to handle these rules.
Types (mechanisms for) of Active Follow-Up:

- Letters
- Listings
- Visits to facility
- Phone calls
- …

Interested Registries

Interested:
Not Interested:

Local Procedures

Local rules also apply here.
NM has a rule to not send letters to American Indian patients (agreement with HIS)
IA: uses patients and informants as first, best source of follow-up information.
AT, LA: NEVER contacts patient.
HI: would only use patient if person has lost to follow-up status. They have to obtain physician consent before contacting the patient for this.
DT: can't contact some patients for FUP because facility wants to do so. If facility can't find information or stops tracking, then registry can contact them again. Patients are last resort, facilities and doctors are first.
ATL: FUP clerk visits some hospitals and looks up info in their files.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Check for facility assigned to obtain follow-up and send list of outstanding patients for the period to that facility. This is an attempt to limit number of people contacting a patient.
In LA and HI, most contacts are letters (some with lists)

Sensitivity

Trigger
Eligible for Active Follow-Up **or**
Response inadequate (no date or date prior to current FUP)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

7.2.2 Perform Follow-up Action

ID: 7.2.2

Description
This could include: generating a query, creating a listing for someone to make a visit to a Facility, making the visit to the Facility, making a phone call, etc.
Note: if contacting patient or an informant, contact information comes from the patient set.
Note: could possibly computerize some of the follow-up letters including query generation and creation of listings for Facility visits
DESIGN NOTE: NM mentioned that they would be interested in a secure web site between the registry and the physicians, so that physicians could send updated patient information to the registry (and hence avoid this task)
DESIGN NOTE: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Manual

Processor
Follow-up Clerk

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules
Registries would like to be able to send outstanding follow-back questions at the same time. This means they have to be able to easily query the follow-back tracking from this process and be able to tell which follow-back needs still must be met.

Sensitivity

Trigger
Type chosen

Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

7.3 Evaluate Active Follow-Up Responses

ID: 7.3

Description

If the evaluation is that follow-up was not successful, they would return to 7.2 Determine Type of Active Follow-up.
Medical coding may be occurring here depending on information received, but it's not very likely. Information of this sort should be passed to 4.0 Match and Consolidate Patient as 'New Patient Set Info.'
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
If follow-back queries were included, then any follow-back responses need to be returned to the follow-back process so the tracking can be updated.

Acknowledgement of the response and determining next steps based on the nature of the response. For example,

The response may be: not my patient, wrong address, "what cancer?" Any of these could then require Follow-Back or new follow-up action.
The response may provide other updated/new information that could be used to update the Patient Set (e.g., new patient address, new patient phone number) where we would then Select Best Values.

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better.
LA and HI ask for information other than follow-up, so this process should be facilitated. HI believes about 60% of responses have non-follow-up information. Also, they feel they need to track all incoming information for HIPAA.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Follow-up clerk

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

If better date is not received, need to try again
If vital status = dead, need to find cause of death.

Sensitivity

Trigger

Response to follow-up query arrives
(and if record arrived**)** Response received
(Follow-back complete)

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

7.4 Process Responses to Follow-Up Queries

ID: 7.4

Description

After a response has been received, the registry staff needs to process any new information provided in the response.
Could include attributes other than Vital Status and Date of Last Contact that would require looking at the Adds/Changes/Deletes for the Data Items.
Since some registries take advantage of the need to contact a physician for follow-up information to include follow-back questions, they are frequently added non-follow-up information in this process. Also, physicians and patients may volunteer additional information that needs to be added to the patient set (better DOB, new physician to contact, change of address, gender, so on)
Could generate abstract facility lead here (if response is 'I sent them to so & so' or Patient mentions they went to whatever facility for treatment)
In some cases, the result may be to delete (or to designate for deletion) treatment set or CTC set or patient set. (usually as a result of other information sent with the follow-up response)
After each change to the data, single field edits would occur. After all changes are 'complete', inter-field edits would occur until. This would continue until all edits passed or were overridden.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
Update 'Follow-up Tracking Information'

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-up Clerk

Location

Central Registry Office
Field Laptop (freestanding) (7.4.3)

Policies/Business Rules

People can be resurrected.
The need to get follow-up information and other information received during follow-up into the system can be implemented in several ways. The registries would prefer to have some kind of record that they can establish a link to so if they need to disassemble the patient (this is really 2 patients and not all the records go together), they don't lose information that was just kind of 'added' in during a phone call. Right now they are using correction records to fill this need. Depending on system design, the add/change/delete history records may fill the need.

Sensitivity

Trigger

FUP info or MP update received **or**

New/Updated org, fac, MP info received **or**
New facility for CTC mentioned

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

7.4.1 Update Profiles

ID: 7.4.1

Description
If information about an organization, facility or Medical practitioner is received and the registry was previously unaware of that entity, the information must be added to the registry's profiles.
Registry desires Name and contact information at a minimum so they can obtain the rest of the information needed in the profile.
See location for note!

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Follow-up Clerk

Location
Central Registry Office

NOTE: field staff may gather information, but the actual update is done in CRO only.

Policies/Business Rules

Sensitivity

Trigger
New/Updated org, fac, MP info received

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

7.4.2 Add Abstract Facility Lead

ID: 7.4.2

Description
If a facility is mentioned with respect to a CTC and it is not currently included in the patient set, the registry needs to create an abstract facility lead so their patient set can be completed.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Follow-up Clerk

Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
New facility for CTC mentioned
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

7.4.3 Select Best Value from Active Follow-Up

ID: 7.4.3
Description
Trying to find most recent date that the vital status was known.
Could include attributes other than Vital Status and Date of Last Contact that would require looking at the Adds/Changes/Deletes for the Data Items.
Since some registries take advantage of the need to contact a physician for follow-up information to include follow-back questions, they are frequently added non-follow-up information in this process. Also, physicians and patients may volunteer additional information that needs to be added to the patient set (better DOB, new physician to contact, change of address, gender, so on)
If the date of contact obtained is prior to the date already known by the registry, follow-up is deemed not successful and they would return to 7.2 Determine Type of Active Follow-up.
In some cases, the result may be to delete (or to designate for deletion) treatment set or CTC set or patient set. (usually as a result of other information sent with the follow-up response)
After each change to the data, single field edits would occur. After all changes are 'complete', inter-field edits would occur until. This would continue until all edits passed or were overridden.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
Update 'Follow-up Tracking Information'
If follow-back is needed and the follow-back response affects a health record, a health record update will need to be generated.
DESIGN NOTE: Security of data item is complicated. They need to not only restrict who has access to a data item and what they can do (read vs write), but also what kind of changes can be made. For example, only select people can change vital status from dead to alive or back date a date of last contact value.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Follow-up Clerk
Computer (selecting best date should be automated)

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules
People can be resurrected.
The need to get follow-up information and other information received during follow-up into the system can be implemented in several ways. The registries would prefer to have some kind of record that they can establish a link to so if they need to disassemble the patient (this is really 2 patients and not all the records go together), they don't lose information that was just kind of 'added' in during a phone call. Right now they are using correction records to fill this need. Depending on system design, the add/change/delete history records may fill the need.

Sensitivity

Trigger
FUP info or MP update received
(Edit complete)
(Follow-back complete)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

7.5 Modify Follow-Up Need

ID: 7.5

Description
Changing information stored about the active follow-up need, modifying the need. These changes may come from the follow-up clerk trying to resolve the need.
Reason for change should be noted.

Interested Registries
Interested:
Not Interested:

Local Procedures
HI and IA are interested in capturing an audit log of this.

Degree of Automation
Semi

Processor
Follow-up Clerk

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
Modification needed

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

8.0 Conduct Follow-Back

ID: 8.0

Description

The purpose of Follow-back is to clarify, confirm or request information. The result of Follow-back may be an abstract, correction record, specific data item values in a letter/phone conversation, or a response that it is not reportable from that data source.

Follow–back queries may include missing information beyond routine follow-up data items, for example: race, treatment, stage, etc.

In most cases this involves Health Record Data. In some cases, this might involve Patient Sets. One example of when Follow Back is performed using Patient Sets is when a new Edit is added (and existing patient sets are run against this new edit) or when the Follow Back need is generated in Matching or Consolidating.

Follow-back is ad hoc as opposed to routine follow-up. Also, data that is requested in follow-back is supposed to be static, follow-up data is supposed to change over time.

Follow-back is not performed on Supplemental Records as there is no facility. If information is in conflict, then follow-back is conducted with the reporting facility or patient.

NOTE: some follow-back is done instantaneously by the user of the process which brings the problem to light (they call the doctor right at that point). This is unlikely to be tracked within this follow-back process. This process will only affect and capture follow-back which has been routed to the follow-back staff.

Implementation consideration: Currently, '8.0 Conduct Follow-Back' is stand-alone and included as part of the processes that use it. An option would be to embed '8.1 Create Follow-Back Query' and '8.3 Evaluate Follow-Back Response' within the processes using it as appropriate.

Processing Death Info:

3. When a DC has been determined to be a new CTC, check DC for physician/facility information. If found, contact source and request abstract. If the source is not an abstract source (possibly a coroner's office) or if the source replies that there isn't any info available to do an abstract, try to get a new physician/facility to contact – patient came from hospital, hospice so on. Contact new source…
4. If there is no source or the trail dead-ends and the registry is unable to obtain additional information, they mark this as a DCO (see glossary).

Interested Registries

Interested:

Not Interested:

Local Procedures

HI: about 90% of registry-created abstracts spawn follow-back

LA: most follow-back needs discovered during abstracting; however, staff just calls hospital.

Currently not tracked well for any registry. HI would prefer better tracking.

Degree of Automation

Semi

Processor

Follow-back Clerk

Follow-back Manager

Abstractors (in field: in follow-back role)

Any Registry staff (logging need for follow-back)

Location

Central Registry Office

Field Laptop (freestanding)
Field Registry Staff Home (logged in)
(can be initiated from Field)

Policies/Business Rules

Uses a specific follow-back form for Physicians
Most likely to follow-back with Medical Practitioners, Facilities, Organizations and Org Reps. Some Registries would NEVER follow-back with Patient or Informants. Others would only do so for certain questions only and probably as a last resort.
Org Reps could include people who work for the registry. I.e., if there is a question to our own abstractor, this would track the question/solution.

Sensitivity

Trigger

Follow-back needed (Includes: New address needed, Critical Missing Values & Response unclear)

(For getting information in & resolving follow-back need)
Response to follow-back query arrives **or**
Response received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.1 Store Follow-Back Need

ID: 8.1

Description

After a follow-back need is identified, it should be stored so that a member of the follow-back staff can retrieve it to generate a follow-back query to the proper facility.
This process must be accessible from all other processes, as a follow-back need can be found almost anywhere.
Tracking should be as automated as possible (who's need, when, …)
Mostly seem to be coming from 4.0 Consolidate patient set and 18.1 Compare and Resolve text to codes (visual editing)

Interested Registries

Interested:
Not Interested:

Local Procedures

This process may not be needed if person who discovers need contacts a source immediately. The amount of tracking that would then occur probably varies by registry and focuses on the response.

Degree of Automation

Semi

Processor

Anyone
Most likely to be Editor/Consolidator/Coder, Case finder/screener, Death Clearance Manager or QC person

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Follow-back needed (Includes: New address needed, Critical Missing Values & Response unclear)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.2 Create Follow-Back Query

ID: 8.2

Description

Create a query for an identified problem (follow-back need) checking to see if there are any related follow-back needs and their current status (are they unanswered or unresolved).

A single follow-back query can relate to several follow-back needs (multiple questions in query). A single need can result in several queries (multiple facilities to follow-back with).

Update 'Follow Back Tracking Information' with the Follow Back Need and its tracking information.

Interested Registries

Interested:
Not Interested:

Local Procedures

HI: if more than 5 questions to one place, would call to find out if the facility/org wants registry staff to come out and help.

LA: if more than 9 questions to one place, would call to find out if the facility/org wants registry staff to come out and help.

Degree of Automation

Semi

Processor

Follow-back Clerk
Follow-back Manager
(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

If person who discovers need contacts a source immediately, the amount of tracking that would occur probably varies by registry and focuses on the response.

They (the registry managers) would need to decide what tracking information they want and how consistently. NCI needs to decide how much flexibility to allow.

Sensitivity

Trigger

Ongoing

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.2.1 Review Follow-Back Needs

ID: 8.2.1

Description

Determine which needs are still open; with whom to follow back (usually org, facility or medical practitioner); determine what the query should be; determine the mechanism (phone, letter, etc); how many needs will be contained in the query.

Implementation consideration: Submitted via Letter, Phone Call, E-mail, Fax, Visit, Database Query, etc.

IF 8.0 is entirely done by person who discovered need, probably wouldn't need this step.

DESIGN NOTE: need to set a flag for the answer is overdue

Interested Registries

Interested:

Not Interested:

Local Procedures

HI: answer is considered overdue after 3 weeks. They would call and verify letter was received.

LA: answer is considered overdue after 2 weeks. They would call and verify letter was received.

Degree of Automation

Semi

Processor

Follow-Back Clerk

Follow-Back Manager

(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)

Location

Central Registry Office

Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Ongoing

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

8.2.2 Generate Follow-Back Query

ID: 8.2.2

Description

After reviewing the follow-back needs, a query addressing the follow-back needs is created (can contain multiple needs) and the communication is initiated by the method decided upon in 8.2.1.

Need to track who sent the response.

Follow-back queries may be modified at this point (while the work is being done) and such changes would need to be tracked.

Follow-Back clerk may process some of the calling, mailing, etc. once a question has been formed and the contact to ask has been determined. Automation (if possible) would also work.

DESIGN NOTE: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-Back Clerk
Follow-Back Manager
(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

Follow-back to PATIENT or INFORMANT is extremely unlikely. (Most registries would never do so.) They usually don't know the answers and the registries don't like to bother them.
If follow-back is spawned by DCO, never use next of kin.

Sensitivity

Trigger

New query needed **or**
Need to redirect need (from 10.3.1)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.2.3 Assign Follow-Back Need to Field Staff

ID: 8.2.3

Description

If a follow-back need is related to a facility that has a registry staff member (or group) that handles all registry interaction with that facility, the follow-back need will be assigned to that person.
This is typically a field abstractor who does the case finding, abstracting, follow-up and follow-back for a particular facility.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA and HI both need this.

Degree of Automation

Probably Semi

Processor

Follow-back Clerk
Follow-back Manager
(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)

Location

Central registry

Policies/Business Rules

Sensitivity

Trigger

Follow-back need for facility with field staff **or**

Need to redirect need **and**
Need directed toward facility with field staff

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.3 Process Follow-Back Response

ID: 8.3

Description

Reading the response, comparing it to the query that was sent, determining if appropriate and sufficient, and determining next action to be taken.
Update 'Follow Back Tracking Info' with the Follow-Back Response and its tracking information. Need to track who received the response and who evaluated it.
May want to indicate that Health Record was also sent as part of the response.
Implementation Strategy: This specifies the disposition, i.e. it determines the next step in the process based on the follow-back response. For example:

Needs to be Abstracted
Needs additional Follow-Back
Needs to go to Resolve Patient Set
<NOTE: A complete list exists in the text on the data flow "Follow Back Disposition">

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better.

Interested Registries

Interested:
Not Interested:

Local Procedures

When this is done and by whom may vary by registry. For example, the person who sent the Query could be the one who receives and evaluates the response in "Follow-Back". Or the person who receives the response may route the response to someone in "Abstracting' who would then "Evaluate the Response".

Degree of Automation

Semi

Processor

Follow-Back Clerk
Follow-Back Manager
(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)
Hopefully Automated return

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Response to follow-back query arrives **or**
Response received **or**

Response obtained

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.3.1 Evaluate Response

ID: 8.3.1

Description

Determine if response fulfills follow-back need. Since 1 query may have several needs, a partial response may fulfill some needs while others remain unresolved. Since 1 need may have several queries, the response may only partially fulfill the need while totally fulfilling to the query.
This response may be coming from active follow-up if follow-up is needed from a source that has outstanding follow-back.
Medical coding may be occurring here, or may be pushed further along process path – where exactly it occurred would be based on disposition.
Need to track who receives the response and who evaluates the response.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-Back Clerk
Follow-Back Manager
(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Response to follow-back query arrives **or**
Response received **or**
Response obtained

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.3.2 Return Follow-Back Response

ID: 8.3.2

Description

After evaluating the response, it should be returned to the person who issued the follow-back request so they may take the appropriate action (e.g. change patient info, approve them for a special study, etc.)
This may be returning information to a process or to a person.
This may be implemented in a variety of ways, including email.

IF 8.0 is entirely done by person who discovered need, probably wouldn't need to do this step
Most answers are feeding into 4.0 Consolidation and 18.1 Compare and Resolve Text to Codes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

??

Processor

??
Hopefully Automated
Otherwise Follow-Back Clerk
(8.0 may be entirely done by person who discovered need, probably wouldn't track, could be any registry staff member)

Location

Central registry

Policies/Business Rules

Sensitivity

Trigger

Response acceptable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.4 Research Follow-Back Need

ID: 8.4

Description

After a follow-back need has been assigned to a field registry staff member, they must attempt to find an answer within the facility specified. This may involve reviewing their prior work (as an abstractor), reviewing the medical records or asking a physician a question. However, they are the sole point of contact from the registry to the facility, so they do the work.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual
Possibly Semi

Processor

Field Abstractor

Location

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Unresolved follow-back need assigned to field staff

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

8.5 Modify Follow-Back Need

ID: 8.5

Description

Changing information stored about the follow-back need, modifying the need. These changes may come from the originator of the need or the person trying to resolve the need.
Reason for change should be noted.

Interested Registries

Interested:
Not Interested:

Local Procedures

HI and IA are interested in capturing an audit log of this.

Degree of Automation

Semi

Processor

Anyone (specifically the anyone who saved the need in the first place)
Follow-back Clerk

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Modification needed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

9.0 Remove Non-CTC Records

ID: 9.0

Description

When a record fails the broad screen and is determined to be not a CTC nor reportable to a special study, it must be removed from the registry's data. This includes removal from the health and supplemental record data store and from the archived submission file.
If one of these records was used for passive follow-up, data integrity demands something must be available – the health record is stripped of restricted information and replaced in the health and supplemental record data store.
DESIGN NOTE: we are unsure of the exact mechanism for dealing with the archived submission cleansing and the duplicate submission check. The suggestion of the moment is to replace the non-CTC non special study record with some sort of check number.
DESIGN NOTE: Seattle does not want gaps in their records. They do not check to see if a non-rpt record was used in passive follow-up, they just remove health information from all such records and retain the

patient demographics and record id. (slide number for path reports). May need to make these processes configurable so that during implementation at a registry, they can decide if they want to only keep FUP records or they want to keep all received.

Interested Registries

Interested:

Not Interested:

Local Procedures

Not all registries wish to clean the archived submission file at this time. Only LA stated a current wish for this ability. (AT had mentioned it at one point, but didn't see need for this at different time)

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office

Policies/Business Rules

John Young from AT at one point believed it's not legal to retain the full record. IMS assumes that means in any form (including archived file)

Sensitivity

Trigger

Periodically

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

9.1 Remove Health Record from Submission

ID: 9.1

Description

When a record fails the broad screen and is determined to be not a CTC nor reportable to a special study, it must be removed from the archived submission file.

DESIGN NOTE: we are unsure of the exact mechanism for dealing with the archived submission cleansing and the duplicate submission check. The suggestion of the moment is to replace the non-CTC non special study record with some sort of check number.

This must be done prior to stripping the record from the health and supplemental data store or it won't be possible to find the correct record in the submission data.

Interested Registries

Interested:

Not Interested:

Local Procedures

Not all registries wish to clean the archived submission file at this time. Only LA and AT stated a current wish for this ability.

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office

Policies/Business Rules

John Young from AT believes it's not legal to retain the full record. IMS assumes that means in any form (including archived file)

Sensitivity

Trigger
Periodically

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

9.2 Search for Passive Follow-up Use

ID: 9.2

Description
A search to determine which non-CTC non special study records were used in passive follow-up so that the health and supplemental record data store can be correctly cleaned.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor
Computer

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Submission cleaned

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

9.3 Replace Health Record

ID: 9.3

Description
If a non-CTC non special study record was used in passive follow-up, some information must be retained for data integrity purposes, but other information in the same record must be stripped for legal purposes. The health record in question is replaced with a stripped version under the same health record ID.
DESIGN NOTE: The information that is retained here needs to be configurable by registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully (This may need to be semi automated)

Processor
Computer
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Non-CTC Record used for Passive FUP
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

9.3.1 Strip Health Record

ID: 9.3.1
Description
Restricted data is stripped from a non-CTC non special study record that was used in passive follow-up.
Only data to be retained: Patient ID (any information used to match the patient, possibly name, SSN, DOB, Accession number), Facility ID, Date of contact.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Fully (This may need to be semi automated)
Processor
Computer (Editor?)
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Non-CTC Record used for Passive FUP
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

9.3.2 Replace Health Record with Stripped Record

ID: 9.3.2
Description
The health record in question is replaced with the stripped version under the same health record ID.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

9.4 Delete Health Record

ID: 9.4

Description

If the non-CTC non special study record was not used in passive follow-up, it is totally blanked out of the health and supplemental record data store.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Non-CTC record not used for Passive FUP

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.0 Manage Registry Operations

ID: 10.0

Description

This is a collection of largely unrelated management tasks.
Keeping track of the work flow (and that the work is flowing). Is data coming in when and how its supposed to? Is data going out when and how its supposed to? Are leads, follow-up and follow-back being dealt with in a timely manner? Are there quality issues in the data the registry is collecting?

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Processor
Mostly initiated by managers
Location
Central registry
Field Laptop (freestanding)
Field Registry Staff Home (logged in)
Policies/Business Rules

Sensitivity

Trigger
Periodically/ongoing
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.1 Manage Abstract Facility Leads

ID: 10.1
Description
Identify open abstract leads per facility.
Assign abstracts per abstractor per facility based on scheduling criteria. In some registries this is more complex: considers distance, time and cost of visiting a facility
Submit requests for patient medical records or abstracts depending on facility. We may go get the information and/or review the information on site.
This would include abstract facility lead aging analysis.
Close leads that have been fulfilled or that are determined to be lost causes.
Purge leads that have been closed for a designated length of time.
Some of these functions may overlap with functions being performed in '2.0 Conduct Abstracting'. If the function is done as part of the job flow, then include in 2.0; otherwise, it is performed here.
Update 'abstract facility lead tracking information'.
DESIGN NOTE: if lead over 6 months old and unassigned, work flow ought to notify someone. (once a week?)
Interested Registries
Interested:
Not Interested:
Local Procedures
LA: crosses off leads as abstracts arrive to facilitate this task. This tracking should be easy or automatic.
Degree of Automation

Processor
Abstractors' manager
Death Clearance manager
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency: HI, LA: continuously
Volume:
Duration: < 1 hour LA/HI: however it's very time consuming to actually resolve the lead.
Quality/Error rate:

10.1.1 Monitor Abstract Facility Leads

ID: 10.1.1
Description
As abstracts arrive, close corresponding abstract facility leads. Could be implemented as something that occurs when abstract has passed 13.0, or something that happens periodically.
Review open abstracts to verify that none have been overlooked (should have been abstracted or should have been closed)
Close leads determined to be lost causes
Purge leads at manager's discretion.
Record comments on any lead as desired.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Abstractors' manager
Death Clearance manager
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Periodically **or**
Ready to close
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.1.1.1 Review AFL's

ID: 10.1.1.1
Description
Periodically, need to review abstract facility leads to determine:
1. Is lead valid? If not, close lead with reasoning (out of area, not cancer/tumor, so on)
2. Is lead filled? If so, close and date. (abstract received from facility, abstraction done by staff. Either check incoming health records or check against appropriate patient set for needed facility view.) Also need to

check if abstract was attempted and not done for a reason which should close the lead. For example, Facility mentioned on DC, but CTC was DOA and no medical records are available (this would be a DCO).
3. Is lead fillable? (has enough time past since diagnosis, that this abstract should be obtained?)
4. If lead is valid, not filled, and fillable, has it been assigned? If so, managerial task of finding out why abstract hasn't been done, depending on date assigned, and cracking the whip. If not, assign it and date when it was assigned.
Review abstract facility leads per abstraction criteria against existing patient set(s) and existing health records.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Abstractors' manager
Death Clearance manager

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.1.1.2 Close AFL's

ID: 10.1.1.2

Description

Once abstract is completed or the decision has been made that a particular abstract is unable to be completed, its status needs to be changed to 'closed.'
This process should be closing any missed AFL's (an abstract came in without being requested that fulfilled the lead, but the lead status was never updated).

Interested Registries

Interested:
Not Interested:

Local Procedures

The determination of what should be closed because it cannot be obtained will probably always be partially human. These rules probably vary by registry.

Degree of Automation

Semi

Processor

Abstractors' manager
Death Clearance manager

Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Ready to close
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.1.1.3 Manually Purge AFL's

ID: 10.1.1.3
Description
The lead's status is manually changed to 'purged.'
This would only happen when there was some reason that the automated purge settings were unacceptable. (Need it purged now, can't wait until its been closed for x months.)
This is more functionality that needs to be included (the ability of a person to purge an item) than a specified need.
Purged items are not normally shown when the database is searched.
Interested Registries
Interested:
Not Interested:
Local Procedures
The determination of what should be purged and can't wait for the automatic purge will probably always be partially human. These rules probably vary by registry.
Degree of Automation
Semi
Processor
Abstractors' manager
Death Clearance manager
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Ready to purge
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.1.1.4 Record Comments

ID: 10.1.1.4
Description
If any changes are made to the lead, a comment should be entered as to what was done and the reason why.
Tracking of decisions.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Abstractors' manager
Death Clearance manager
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Want to record comments
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.1.2 Investigate Open AFL's

ID: 10.1.2
Description
If an abstract facility lead has been open for some extended period of time, someone needs to find out why. Investigating could be in the form of emails, letters, phone calls, etc. to the facility.
This could result in a reminder to the staff to track the reason why AFLs that can't be abstracted and to close the leads.
Trying to prevent CTCs from being overlooked and falling through the cracks.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Manual
Processor
Abstractors' manager
Death Clearance manager
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Going to keep in open status
Metrics
Frequency:
Volume:

Duration:
Quality/Error rate:

10.1.3 Automatically Purge AFL's

ID: 10.1.3

Description

After being closed for some specified amount of time the computer changes the status of the lead to 'purged.'
Purged items are not normally shown when the database is searched.

Interested Registries

Interested:
Not Interested:

Local Procedures

Each registry needs to be able to set the amount of time a lead remains closed before it is purged. Some may chose to never purge.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.2 Manage Health Information Acquisition

ID: 10.2

Description

Verifying that the health information the registry expects to receive and needs to have in order to provide complete, high quality CTC information is actually arriving in the registry in a timely manner. Where delays are occurring, putting more effort into obtaining the information (sending out requests or staff).
Review number of CTCs sent per facility against history of number of CTCs sent per facility; review abstract facility leads, requests for specific records and need for general records, review whether information is being received from special studies and data exchange partners.
This process also includes punitive actions take when data is not sent to the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Each registry has to determine what their expected submission rates are for each facility every year. They also must decide which data exchange agreements they will enter into. It should be relatively easy for them to add parameters to this process.
Need ability to Manage Abstractors trips – part of scheduling criteria. In some registries with wide, hard to get to places (NM especially), registry

schedules a 'circuit' and needs to plan: which abstracts from facility, order of facilities, travel time/accommodations, etc. (also noted in Assign Abstractor 2.2)

Degree of Automation

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

While facilities are the source which generates health records, some facilities send these records to a parent organization for storage. The registry may have to contact the organization to get access to these records.
Becoming critical task for ATL, Medicaid funding will be dependant on prompt hospital reporting of diseases.

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume: HI: 20-50 sources;
Volume: LA: 120 facilities + dr offices + 7 CA regions + 2 states. (they get about 1800 rpts from drs)
Duration:
Quality/Error rate:

10.2.1 Monitor Health Info Acquisition

ID: 10.2.1

Description

Review abstract facility leads, requests for specific records, review whether information is being received from special studies and data exchange partners.
Requests may be sent or re-sent, closed or purged as seems appropriate.
DESIGN NOTE: Would like to use bar codes on outbound communications that expect responses to facilitate tracking.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.1 Review Outstanding Health Info Requests

ID: 10.2.1.1
Description
For all outstanding requests (including those based on abstract facility leads), data exchange and special study agreements, determining if a request should be sent, resent, closed or purged.
Using Abstract Facility Leads enables registry to back up the assertion that the facility should have information about a particular CTC even when the facility says they don't. Continued inability by facility to produce information about such a CTC would trigger 10.2
DESIGN NOTE: would be nice if work flow could notify manager that a health info request was 'past due'. The time span between request and due date should probably be configurable at registry.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Abstractors' Manager
Registry Manager
Location
Central Registry Office
Field Registry Staff Home (logged in)
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.2 Send Request for Specific Health Records

ID: 10.2.1.2
Description
Submit requests for health information needed. We may go get the information, review the information on site, or request that it is sent to us. This may be a re-sent version of a previous request.
These may go to facilities or organizations that are obligated to report to the registry, data exchange partners and special study groups who agreed to return data to the registry.
Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Processor
Abstractors' Manager
Registry Manager
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Need to request health records
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.3 Close Health Info Request

ID: 10.2.1.3
Description
Once the request has been fulfilled or the decision has been that a particular request is going to remain unfulfilled, its status needs to be changed to 'closed.'
Interested Registries
Interested:
Not Interested:
Local Procedures
Decision concerning a request that will never be filled probably varies by registry.
Degree of Automation
Semi
Processor
Abstractors' Manager
Registry Manager
Location
Central Registry Office
Field Registry Staff Home (logged in)
Policies/Business Rules

Sensitivity

Trigger
Ready to close
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.4 Record Comments

ID: 10.2.1.4
Description
If any changes are made to a request, a comment should be entered as to what was done and the reason why.

Tracking of decisions by updating 'information acquisition tracking information'.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Want to record comments

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.5 Manually Purge Health Info Request

ID: 10.2.1.5

Description

The request's status is manually changed to 'purged.'
This would only happen when there was some reason that the automated purge settings were unacceptable. (Need it purged now, can't wait until its been closed for x months.)
This is more functionality that needs to be included (the ability of a person to purge an item) than a specified need.
Purged items are not normally shown when the database is searched.

Interested Registries

Interested:
Not Interested:

Local Procedures

The determination of what should be purged and can't wait for the automatic purge will probably always be partially human. These rules probably vary by registry.

Degree of Automation

Semi

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Ready to purge

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.6 Search for ID Issues

ID: 10.2.1.6

Description

Checking health records received from each facility to verify that no ID has been skipped within a given range and that no ID has been assigned multiple times.
This includes the verification of a facility's accession numbers and verification of a lab's slide numbers.
A request that documentation for the missing ID be sent or the duplicated ID be corrected.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.1.7 Update ID Problem Info

ID: 10.2.1.7

Description

When a reason for a missing accession number is received by the registry from a health record source, this reason must be retained for future reference.
If a duplicated accession number is corrected (new number assigned to a person), the information is corrected and the resolution retained.
Other tracking information about the problem will also be stored by this process.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Response received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.2 Get Health Records

ID: 10.2.2

Description

This involves sending a registry staff member out to a facility to get needed health records.
Important to track that this has been done because frequently the registries charge for this.
This usually happens when requests for records have not been fulfilled.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Field Abstractor

Location

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Need to go get records in person

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.3 Review Info Received vs. Expected

ID: 10.2.3

Description

Periodically a registry staff member needs to review number of CTCs sent by each facility as compared to the history of the number of CTCs sent by that facility.

If the number of records received is not satisfactory, a request might need to be reissued or some state agency might need to be notified of the deficiency.
Would include verifying that any special study that was supposed to send information to the registry has done so.
Would like to get a report by facility counting total records received, number of reportable records received and number of CTCs received (if received 3 records about the same CTC, would be counted 3 times in first and second report, but only 1 time in the last report)

Interested Registries

Interested:
Not Interested:

Local Procedures

NJ: want to be about to tell that follow-up information has been received from special studies. The follow-up information would be generated when the study contacted the patient about participating.

Degree of Automation

Manual

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency: LA: Weekly; HI: Monthly
Volume:
Duration:
Quality/Error rate:

10.2.4 Send Request for General Health Records

ID: 10.2.4

Description

Sending a request to a facility/organization for health records. This is a general request, such as 'please send all abstracts for the year'.
This process could be triggered when the registry does not receive the expected number of health records for a facility or when a facility does not meet State Regulations. It may also be triggered if the request is scheduled (ask for disease index on June 1st)

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Abstractors' Manager
Registry Manager

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Expected records not received **or**
State regulations not met **or**
Current date > scheduled date (for scheduled requests)

Metrics
Frequency:
Volume: LA: 10-20 a year (most places send stuff automatically)
Volume: HI: 20-30 phone calls, monthly reminders and annual request for disease index (about 20)
Duration:
Quality/Error rate:

10.2.5 Notify State Agency of Deficiency

ID: 10.2.5

Description
If the number of records being received from a particular facility is well below the expected number, the state needs to be made aware of the deficiency.

Interested Registries
Interested:
Not Interested:

Local Procedures
Varies by state law.

Degree of Automation
Semi

Processor
Registry Manager

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
State regulations not met

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.2.6 Automatically Purge Health Info Requests

ID: 10.2.6

Description
After being 'closed' for a certain amount of time, the computer sets the status of health information requests to 'purged.'
Purged items are not normally shown when the database is searched.

Interested Registries
Interested:
Not Interested:

Local Procedures
Registry needs to be able to set length of time. Some registries may choose to not purge.

Degree of Automation
Fully

Processor
Computerized
Location
Central Registry Office
Field Registry Staff Home (logged in)
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.3 Manage Follow-Back Queries

ID: 10.3
Description
This process involves overseeing all follow-back operations to ensure timely responses and accurate information.
Involves reviewing the tracking of follow-back needs (requests) vs. follow-back queries generated; follow-back queries vs. responses, follow-back needs vs. follow-back responses (they're not directly correlated via queries, since a query can pertain to several needs; and a response pertains to a query, not a need).
DESIGN NOTE: must be easy to track or people won't do it. This does imply that the managers (people) will enforce tracking being done.
Interested Registries
Interested:
Not Interested:
Local Procedures
HI: resend/redirect after 3 weeks that a query has been sent
LA: resend/redirect after 2 weeks that a query has been sent
Degree of Automation
Semi
Processor
Follow-Back Manager
Death Clearance Manager
Editor/Consolidator/Coder
Individual who asked question
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules
Implementation Consideration: Would be nice to have some sort of time based trigger that the computer could generate warnings about old, outstanding follow-back queries.
Sensitivity

Trigger
Periodically
Metrics
Frequency: LA& HI: ongoing
Volume:
Duration: LA: follow-back has full time manager + 3 supporting staff

Quality/Error rate:

10.3.1 Monitor Follow-Back Queries

ID: 10.3.1

Description

Involves reviewing the tracking of follow-back needs (requests) vs. follow-back queries generated; follow-back queries vs. responses, follow-back needs vs. follow-back responses (they're not directly correlated via queries, since a query can pertain to several needs; and a response pertains to a query, not a need).
Making sure that follow-back responses are being received in a timely manner and that the follow-back needs are being closed.
Can track stats by facility and org or by individual submitting or by response times, etc.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-Back Manager
Death Clearance Manager
Editor/Consolidator/Coder
Individual who asked question

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.3.1.1 Review Follow-Back Queries

ID: 10.3.1.1

Description

Review outstanding Follow Back queries to see which ones need to be pushed to obtain answers. Make sure that queries which have been responded to are closed and that the corresponding follow-back needs that have been resolved have been closed.
If queries have not been answered, may want to re-send old query but keep track of how many times it has been sent, or at least that it has been re-sent. May want to send same query, but to different facility or organization. May want to vary the method used (phone call or visit instead of letter)
Should also verify that all follow-back needs have corresponding queries.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Processor
Follow-Back Manager
Death Clearance Manager
Editor/Consolidator/Coder
Individual who asked question
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.3.1.2 Close Follow-Back Query

ID: 10.3.1.2
Description
After receiving a follow-back response or after determining that a response will never be received, the query's status should be set to 'closed.' The follow-back need should at least have a comment added noting the query has been closed.
Interested Registries
Interested:
Not Interested:
Local Procedures
The determination of what should be closed because it cannot be obtained will probably always be partially human. These rules probably vary by registry.
LA & HI: would not close follow-back need because no response received; they are ever hopeful that someday they may resolve it. Other registries are likely to feel similarly
Degree of Automation
Semi
Processor
Follow-Back Manager
Death Clearance Manager
Editor/Consolidator/Coder
Individual who asked question
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Ready to close
Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.3.1.3 Contact Via Another Method

ID: 10.3.1.3

Description

If no response to a follow-back query has been received or if the current method was unsuccessful, a different method of contact attempted.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-Back Manager
Death Clearance Manager
Editor/Consolidator/Coder
Individual who asked question

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Going to contact again

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.3.1.4 Manually Purge Follow-Back Query

ID: 10.3.1.4

Description

The follow-back query's status is set to 'purged.'
This would only happen when there was some reason that the automated purge settings were unacceptable. (Need it purged now, can't wait until its been closed for x months.)
This is more functionality that needs to be included (the ability of a person to purge an item) than a specified need.
Purged items are not normally shown when the database is searched.

Interested Registries

Interested:
Not Interested:

Local Procedures

The determination of what should be purged and can't wait for the automatic purge will probably always be partially human. These rules probably vary by registry.

Degree of Automation

Semi

Processor

Follow-Back Manager
Death Clearance Manager
Editor/Consolidator/Coder
Individual who asked question

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Ready to purge

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.3.2 Automatically Purge Follow-Back Query

ID: 10.3.2

Description

After a query has been 'closed' for a specified amount of time, the computer sets the status of the follow-back query to 'purged.'
Purged items are not normally shown when the database is searched.

Interested Registries

Interested:
Not Interested:

Local Procedures

Registry needs to be able to set length of time. Some registries may choose to not purge.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.4 Perform Reliability Studies

ID: 10.4

Description

An effort to make the registry staff's work more consistent, more accurate and more confident (and probably quicker) through group review sessions where less experienced staff can pick the brains of those who are more experienced.
See Location note!

EXAMPLE 1: Review odd and challenging CTCs and identify those suitable for training. Distribute CTC information to abstractors. Allow them to create abstract and review as a group the results. (This exercise involves 2.0 (abstracting) and 18.1 in the name of reliability studies.)
EXAMPLE 2: Each abstractor and each editor is reviewed roughly twice per year by having a batch of 30-40 of their abstracts reviewed by QC coordinator. All abstractors (including facility abstractors) get this treatment. (This review involves doing 18.1 in the name of reliability studies.)
EXAMPLE 3: Based on the SEER Quality Profile (either by NCI or registry's own version), specifically aimed reliability projects may be initiated to address problem areas. If a particular accuracy or completeness score is very low, this special reliability study would attempt to rectify the problem.
If reliability study is a SEER study, only SEER reportable cases are used.
Also may include:
Re-abstracting to verify that the correct data is being collected
Re-case-finding to verify that the correct patients are being examined

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Manual

Processor
Registry Manager
Managers
Abstractor
Editor/Consolidator/Coder
Super Editor
QC person

Location
Central Registry Office
Field
NOTE: sometimes training occurs outside the registry where the training is being provided by a registry staff member to other registry staff members and people external to the registry. It's not necessarily happening on a laptop or while signed in.

Policies/Business Rules
This allows opportunity for providing training and improving quality and consistency of data (such as abstracts) created.
Senior/Lead processor (such as abstractors) must be in attendance.

Sensitivity

Trigger
Periodically

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.5 Manage Information Reporting Obligations

ID: 10.5

Description

Manage the outgoing data submitted by the Registry to other organizations. Includes Special Studies, SEER submissions, information shared with other Registries, data exchange agreements, etc.
Review obligations and any calendar dates associated with them. Verify that information is being sent out in a timely manner and deadlines are being met.
If a request is found to be outstanding it should be investigated as to why the data was not sent.

Interested Registries

Interested:
Not Interested:

Local Procedures

While some obligations are consistent, there are many that are specific to each registry. The registry staff has to be able to modify information/obligations feeding this process easily.

Degree of Automation

Processor

Registry Manager
PI

Location

Central Registry Office

Policies/Business Rules

DESIGN NOTE: would be nice if the sending of records to data exchange partners could be automated (quarterly) so that information is sent out with minimal staff interaction.
Probably would appreciate some automation of the SEER submission as well. At least email reminders that whatever submission is due in x days.

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration: HI: 1 day a month; LA: 15 min a day
Quality/Error rate:

10.5.1 Monitor Information Requests

ID: 10.5.1

Description

Make sure that information requests are being sent when they are scheduled to as set in the Data Exchange Agreement.
Initiate reporting tasks which are due in X days
Close obsolete or completed information requests

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Registry Manager
PI
(May be a role, not a person: Information Distribution Manager)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.5.1.1 Review Information Requests

ID: 10.5.1.1

Description

Entails reviewing requests to ensure that they are being sent when scheduled with correct and accurate information
Standing information requests can include Data Exchange Agreements, SEER and local submissions, Special study reporting.
Also includes reviewing open information requests to see why they are open and reviewing open information request problems to see why they are open.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Registry Manager
PI
(May be a role, not a person: Information Distribution Manager)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.5.1.2 Initiate Reporting Task

ID: 10.5.1.2

Description

This process ensures that standing requests are sent out on time.
Data exchange agreements, special studies and SEER and local submissions that are due repeatedly at regularly scheduled intervals are
DESIGN NOTE: please automate this as much as possible. Ie, have workflow send email to person or group assigned to task.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Registry Manager
PI
(May be a role, not a person: Information Distribution Manager)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Standing Request Due

Metrics

Frequency:
Volume: HI: about 10 standing; LA: about 150 standing
Duration:
Quality/Error rate:

10.5.1.3 Close 'Dead' Information Requests

ID: 10.5.1.3

Description

Information requests that no longer need to be fulfilled should have their status set to 'closed.' However they should NOT be deleted in case they are reopened.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Registry Manager
PI
(May be a role, not a person: Information Distribution Manager)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Ready to Close

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.5.2 Investigate Unfulfilled Information Requests

ID: 10.5.2

Description

Involves trying to determine why an information request has gone unfulfilled and highlighting that request for managerial attention. The same for unresolved information request problems.
May include specifically assigning a request or problem to a staff member.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Registry Manager
PI
(May be a role, not a person: Information Distribution Manager)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Open request needs to be completed **or**
Unresolved problem needs to be resolved

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.6 Manage Follow-Up

ID: 10.6

Description

Includes those activities necessary to ensure follow-up is occurring in a timely manner and that the responses are adequate.
Could include activities to track efficiency and effectiveness of follow-up. For passive follow-up, periodically review files being purchased and follow-up information being obtained through them to assess whether the expenditure is worthwhile. Review quality of data being received (50% hit rates doesn't help if 49% have bad information).
For active follow-up, review of successful methods should be happening in 7.2 (determine type of active follow-up). May be of interest to review hospital and medical practitioner response rates overall so that these data stores could be updated with information about who/what is a good/timely source or unlikely source of information. Would also review up-to-date follow-up information by facility looking for overly low rates. Review outstanding Follow-up queries to see which ones need to be pushed to obtain answers. Make sure that queries which have been answered/resolved have been closed. Resolution may have occurred during passive follow-up.

Interested Registries

Interested:
Not Interested:

Local Procedures

Field abstractors have to monitor their task list, but LA and DT did not believe this was truly management. Field staff makes single attempt to gather follow-up and returns findings (or lack thereof to registry).
HI: resend/redirect after 3 weeks that a query has been sent
LA: resend/redirect after 2 weeks that a query has been sent

Degree of Automation

Processor

Registry Manager would probably be interested in the passive follow-up dollars vs data.
The following would be interested in active follow-up resources
Follow-up Manager
Follow-up clerk

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency: LA: ongoing; HI probably ongoing, but they don't have good tracking currently so aren't sure.
Volume:
Duration: LA: 1-2 hours a day (1 person)
Quality/Error rate:

10.6.1 Monitor Active Follow-Up Queries

ID: 10.6.1

Description

Involves reviewing all active follow-up queries to ensure that responses arrive in a timely manner and are accurate
Closing those queries which are obsolete or have been determining that no answer is expected

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-up Manager
Follow-up clerk

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:

Duration:
Quality/Error rate:

10.6.1.1 Review Active Follow-Up Queries

ID: 10.6.1.1

Description

Periodically reviewing all active follow-up queries to ensure that accurate responses are being received. Also includes checking for queries that have been open for too long and checking for various other problems.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Follow-up Manager
Follow-up clerk

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.6.1.2 Close Active Follow-Up Query

ID: 10.6.1.2

Description

All follow-up queries that have received an adequate response or the determination has been made that no response will ever be received need to have their status set to ‘closed.’

Interested Registries

Interested:
Not Interested:

Local Procedures

The determination of what should be closed because it cannot be obtained will probably always be partially human. These rules probably vary by registry.

Degree of Automation

Semi

Processor

Follow-up Manager
Follow-up clerk

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Ready to Close

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.6.1.3 Manually Purge Active Follow-Up Query

ID: 10.6.1.3

Description

The follow-up query's status is set to 'purged.'
This would only happen when there was some reason that the automated purge settings were unacceptable. (Need it purged now, can't wait until its been closed for x months.)
This is more functionality that needs to be included (the ability of a person to purge an item) than a specified need.
Purged items are not normally shown when the database is searched.

Interested Registries

Interested:
Not Interested:

Local Procedures

The determination of what should be purged and can't wait for the automatic purge will probably always be partially human. These rules probably vary by registry.

Degree of Automation

Semi

Processor

Follow-up Manager
Follow-up clerk

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Ready to Purge

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.6.2 Automatically Purge Active Follow-Up Query

ID: 10.6.2

Description

After a query has been 'closed' for a specified amount of time, the computer sets the status of the follow-back query to 'purged.'
Purged items are not normally shown when the database is searched.

Interested Registries

Interested:
Not Interested:

Local Procedures

Each registry needs to be able to set the amount of time a query remains closed before it is purged. Some may choose to never purge.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7 Manage IT Operations

ID: 10.7

Description

Processes allowing the IT staff to control their environment and maintain it. The sub-tasks are probably not exhaustive; we tried to capture the ones that would affect the system.

DESIGN NOTE: any of these tasks that require locking the database would affect 11.5

DESIGN NOTE: they want multiple system administrators (shocking, I know).

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

IT Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Periodically (probably nightly) **or**
Table needed **or**
Table modification needed **or**
New data mart required **or**
New network configuration desired **or**
Software change desired **or**
Global logoff needed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.1 Back-up Database

ID: 10.7.1

Description

Copying the database to secondary location so that it can be retrieved in case on accidental corruption.
This would affect all database tables in the BOM. There would probably be a parallel data storage area.
First: lock Live database so that no changes could be made (that is why this will likely be at night). **DESIGN NOTE**: if some kind of holding pattern for data to be entered to the live database could be instituted, this could happen during the day and all pending changes would be applied after the database was unlocked
Second: copy the Live database into the Back-up database
Third: unlock the Live database.
DESIGN NOTE: I'm not familiar with how this normally works, but should there be a step 2a, Back-up database is verified against Live?
DESIGN NOTE: registries would like an 'up to the minute' (but the night before is close enough) data base to run reports from. Can we either use this one or create a second reporting DB at the same time?

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor

Location
CRO

Policies/Business Rules

Sensitivity

Trigger
Periodically (probably nightly)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.2 Add DB Table

ID: 10.7.2

Description
Since all registries have local requirements and they run a multitude of special studies, they need the ability to add a new table to the database. This would included adding meta data about the data items contained in the database, the valid values and related meanings for the data items, any related edits that need to be implemented, etc.
This will most likely be related to the Patient set information, but could affect any data area.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor

IT Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Table needed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.3 Modify DB Table

ID: 10.7.3

Description

Since requirements change over time, the registries need the ability to modify existing tables.
This includes adding new data items and modifying the coding schemes and related edit rules of existing data items.
This would most likely affect patient set data, but could affect any data area. The table being modified may be standard to registry specific.
DESIGN NOTE: SEER changes may be implemented centrally and then distributed; it probably depends on the easiest method of implementation.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

IT Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Table modification needed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.4 Define Data Mart

ID: 10.7.4

Description

Setting up the parameters of a data mart or modifying the same.
Parameters include what data items should be accessed, the timing of updates to the data mart, the final form of the data mart.
The request for a data mart would likely come from a manager or from the Information Distribution staff for use in 12.0 Generate Reports,

Extracts and Registry Controlled Files. They may also be based on a Special Study's needs.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

IT Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

New data mart required **or**
Data mart modification required

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.5 Fill Data Mart

ID: 10.7.5

Description

Populating the data mart with current data according to the specifications. This would include the initial population as well as the routine updates.
The timing of updates should be part of the specifications.
This could access any data table in the database.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.6 Modify Network Configurations

ID: 10.7.6

Description

Making changes to the registry network configurations.
If the change will affect the database, should allow for some method of locking the database (if needed) and for testing the database after the configurations have been changed to verify that everything is okay.
This shouldn't change anything in the database, but would require access and setting controls.
NOTE: actual process of modifying the network configurations is out of scope.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM mentioned single user mode – database is not completely locked, person doing the update can work with system to verify that it is working.

Degree of Automation

Semi

Processor

IT Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

New network configuration desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.7 Update Software

ID: 10.7.7

Description

Adding software, installing new versions and applying patches
If the change will affect the database, should allow for some method of locking the database (if needed) and for testing the database after the configurations have been changed to verify that everything is okay.
This shouldn't change anything in the database, but would require access and setting controls.
This would include when a new SEER DMS version was rolled out.
NOTE: Actual process of updating software, etc is out of scope

Interested Registries

Interested:
Not Interested:

Local Procedures

NM mentioned single user mode – database is not completely locked, person doing the update can work with system to verify that it is working.

Degree of Automation

Semi

Processor

IT Staff

Location

CRO

Policies/Business Rules

Sensitivity

Trigger
Software change desired
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.7.8 Notify Users to Log-off

ID: 10.7.8
Description
If the system is being locked or access is being restricted by another 10.7 process, all users that are currently logged on must be notified to save and log off.
DESIGN NOTE: There should be some advanced notice whenever possible. Email is not sufficient, possibly a pop-up notification? Notice needs to be sent to remote access people as well.
DESIGN NOTE: Needs an interface screen to IT staff if log-off need is not caused by other 10.7 tasks. If 10.7 spawned need, would be fully automated.
DESIGN NOTE: May be best to use Access History data store, Log-in and Log-off History (anyone who has logged in without logging off should be notified)
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
IT Staff
Computer (spawned by 10.7 task, fully automated)
Location
CRO
Field Home
Policies/Business Rules

Sensitivity

Trigger
Global log-off needed
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.8 Manage Supplemental Info Acquisition

ID: 10.8
Description
Verifying that the supplemental data the registry expects to receive and needs to have in order to provide complete, high quality CTC information is actually arriving in the registry in a timely manner. Where delays are

occurring, putting more effort into obtaining the information (sending out requests).
Verify that the files that have been received contain complete data. For example, may run frequencies by month and year to verify that all months of data are included in the file.
Verify that requests which have been sent out have been filled (since registry is usually paying for files, this is very important) and the requests are going out in timely manner.
Update 'Supplemental acquisition tracking info'
Supplemental information includes (but is not limited to):
- DMV records
- CMS records (Medicare/Medicaid enrollment)
- Insurance Demographic information
- (HMO)
- Death certificate files
- Voter registration files
- IRS records
- State birth records

Interested Registries

Interested:
Not Interested:

Local Procedures

Each registry has to decide what files they want, when they need them and who they need them from. It should be relatively easy for them to add parameters to this process.
DT: these files are free: VSB and DMV b/c state government; CMS has agreement with SEER.

Degree of Automation

Semi

Processor

Registry manager
Follow-up Manager
IT Staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.8.1 Monitor Supplemental Records Requests

ID: 10.8.1

Description

Reviewing all supplemental requests and agreements to ensure prompt and accurate delivery
Verify that the files that have been received contain complete data. For example, may run frequencies by month and year to verify that all months of data are included in the file.
Verify that requests which have been sent out have been filled (since registry is usually paying for files, this is very important) and the requests are going out in timely manner.
Closing and purging requests and re-issuing requests as needed.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Registry manager
Follow-up Manager
IT Staff
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.8.1.1 Review Outstanding Supplemental Records Requests

ID: 10.8.1.1
Description
For any supplemental records request that has not been filled by certain length of time, an investigation into why it's unfulfilled should be launched.

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Registry manager
Follow-up Manager
IT Staff
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.8.1.2 Re-send Request for Supplemental Records

ID: 10.8.1.2

Description

After reviewing an outstanding records request, the request might be reissued to obtain the data.

Tracking information should be updated to reflect that this the xth time that this request has been sent.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Registry manager

Follow-up Manager

IT Staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Expected File Not Received

Metrics

Frequency:

Volume: HI: VERY rare

Duration:

Quality/Error rate:

10.8.1.3 Close 'Outstanding' Supplemental Records Request

ID: 10.8.1.3

Description

All supplemental records request that have received an adequate response or the determination has been received that no response will ever be made need to have their status set to ‘closed.’

It is unlikely that a request that involves money will be closed without the receipt of a usable file. Tracking of request should include amount paid if any.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Registry manager

Follow-up Manager

IT Staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Ready to Close
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.8.1.4 Manually Purge Supplemental Records Request

ID: 10.8.1.4
Description
The status of the request is set to 'purged.'
This would only happen when there was some reason that the automated purge settings were unacceptable. (Need it purged now, can't wait until its been closed for x months.)
This is more functionality that needs to be included (the ability of a person to purge an item) than a specified need.
Purged items are not normally shown when the database is searched.
Interested Registries
Interested:
Not Interested:
Local Procedures
The determination of what should be purged and can't wait for the automatic purge will probably always be partially human. These rules probably vary by registry.
Degree of Automation
Semi
Processor
Registry manager
Follow-up Manager
IT Staff
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Ready to Purge
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.8.2 Send Request for Supplemental Records

ID: 10.8.2
Description
Sending a request to a facility/organization for information about patients in its area. This is based on calendar of events, when this file is needed by the registry and when it is available from the organization that creates it.
Interested Registries
Interested:
Not Interested:
Local Procedures
HI: has some scheduled – request for voters registration in Dec (after Nov elections)

Degree of Automation
Semi
Processor
Registry manager
Follow-up Manager
IT Staff
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Current date > scheduled date
Metrics
Frequency:
Volume: HI: about 5 times a year
Duration:
Quality/Error rate:

10.8.3 Automatically Purge Supplemental Records Requests

ID: 10.8.3
Description
After a request has been 'closed' for a specified amount of time, the computer sets the status of the request to 'purged.'
Purged items are not normally shown when the database is searched.
Interested Registries
Interested:
Not Interested:
Local Procedures
Each registry needs to be able to set the amount of time a request remains closed before it is purged. Some may choose to never purge.
Degree of Automation
Fully
Processor
Computerized
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.8.4 Review Passive Follow-Up Effectiveness

ID: 10.8.4
Description
For passive follow-up, periodical review of files that were purchased and follow-up information being obtained through them to assess whether the expenditure is worthwhile. Review quality of data being received (50% hit rates doesn't help if 49% have bad information).

Would also review up-to-date follow-up information by facility looking for overly low rates.
This would likely involve some kind of report against the MATCH entities or ACD to determine when the source of a change to 'date of last contact' was based on a particular kind of supplemental record. (ACD where data item=date of last contact & where ACD is cause by SUPPLEMENTAL RECORD matches to PATIENT & where SUPPLEMENTAL RECORD type= record of interest (DMV, etc)

Interested Registries
Interested:
Not Interested:

Local Procedures
HI: doesn't do this, they know their sources are effective
LA: does this yearly not to discard a source but to determine the order in which to contact sources.
NJ: would be interested in having an automatically generated standard report that is created after a supplemental file is run and indicates the results (number of patients updated, number of resurrection attempts).

Degree of Automation
Semi

Processor
Follow-up Manager
Registry Manager

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Periodically

Metrics
Frequency: LA: Yearly
Volume:
Duration:
Quality/Error rate:

10.8.5 Automatically Purge Supplemental Records

ID: 10.8.5

Description
After a set amount of time, if a registry has agreed to destroy the supplemental records received, they must be removed from the submission information (the copy kept for archive purposes) as well as from the Health and supplemental records data store.

Interested Registries
Interested:
Not Interested:

Local Procedures
The need and timing for this task is decided by registry and supplemental source.

Degree of Automation
Fully

Processor
Computerized

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Periodically

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.9 Manage Supporting Data Stores*

ID: 10.9

Description
NOTE: this is currently hard to maintain. Any improvements here would probably be a good thing.

As new information is received by the registry, the supporting data stores must be updated.
New information of this type may be indirectly acquired any time new records are received. They may also be directly acquired from Data Sources.
Some changes to internal data stores, such as rules, criteria, and type of… stores, may be caused by registry policy decisions.
See location note!
Note: these will be investigated (identified and specified) in more detail as data maintenance needs are identified later in the development life cycle.
DESIGN NOTE: when a change to RULES are made that are a central change (affect all registries), would need to provide utility to update the appropriate data store, a utility to update the attributes in the database (if needed), and a utility to update the data (if needed). So a change to ICD-O-4 would require a utility to incorporate the conversion rules, a utility to add the ICD-O-4 to the CTC object and a utility to convert the ICD-O-3 data to ICD-O-4.
Data stores of this sort include (but aren't limited to):

- Org., Facility and Medical Practitioner Profile
- SEER Rules, all variations, Sub groups in 2.0
- Local Rules, all variations, Sub groups in 2.0
- Other Rules, Sub groups in 2.0
- Abstraction Criteria
- Scheduling Criteria
- Surname File
- Data Exchange Agreements
- Data Extraction Rules
- Type of Media
- All other 'Type of …' data stores
- Conversion Rules
- Resolution Criteria
- Census Tract Data

Interested Registries
Interested:
Not Interested:

Local Procedures
LA: might delete something they were sure was obsolete, but more likely not to do so.

Degree of Automation
Semi

Processor
Coder

Registry Manager
IT Staff
Office assistant

Location

Central Registry Office

Information may be gathered in the field, but would only modify the data stores in the central registry.

Policies/Business Rules

Sensitivity

Trigger

Periodically **or**
New supporting data received

Metrics

Frequency: LA& HI: ongoing as new information is learned. Cleaning (purging or marking physicians as deceased) not done as often as adding/updating.
Volume:
Duration:
Quality/Error rate:

10.10 Update Patient Set with Randomly Obtained Knowledge

ID: 10.10

Description

When knowledge about a patient is obtained from random sources, registry staff sees them in the hospital, lives next door, etc., the mechanism for getting that information into the patient set.
When knowledge is obtained in abstracting or follow-up this information goes directly to 4.0 Match and Consolidate Patient Set (probably straight into 4.x.3 consolidate xxx info registry view.) but if the knowledge is obtained outside of those tasks, this process is the first contact the data has with the registry systems.
DESIGN NOTE: Registries would like a web based reporting tool for physicians and facilities so they sign into a secure web site (account and password provided by registry) and can provide information to the registry as it comes to their attention. Need to decide if access to patient is listing or a search. The registries would then decide to accept or reject the information.

Interested Registries

Interested:
Not Interested:

Local Procedures

AT: close to submission time, FUP dates for patients known by registry staff may be updated.

Degree of Automation

Manual
Semi

Processor

Registry staff

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Random knowledge regarding patient acquired

Metrics

Frequency:
Volume: HI: happens a lot
Duration:
Quality/Error rate:

10.10.1 Determine if Permissible to Add Information

ID: 10.10.1

Description

Before any information can be added to the system, the reporting source needs to be verified as being valid.

DESIGN NOTE: Would be nice if the registry could build a standard list of acceptable sources after roll-out. Then whoever acquired the knowledge can easily check if it's acceptable and apply one reason to multiple data items. This list would have to be approved by the manager.

Interested Registries

Interested:
Not Interested:

Local Procedures

The rules regarding this likely vary widely by registry.
For example, a possible rule is if the CTC patient is a registry staff member's neighbor, date of last contact may be updated.

Degree of Automation

Manual

Processor

Manager
Other Registry Staff

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

HI: would have to be a 'reliable' source
LA: only would consider allowing this if it was follow-up and it was close to submission

Sensitivity

Trigger

Random knowledge regarding patient acquired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.10.2 Determine if Information in Patient Set

ID: 10.10.2

Description

After determining that the randomly obtained information is permissible, a check should be made to see if the information is all ready in the patient set.

If the information is currently not found in the patient set, 4.0 processes should be completed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Processor
Manager
Other Registry Staff?
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Permissible to add information
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.11 Manage Staff Productivity

ID: 10.11
Description
Registry Manager would generate report by staff ID by task type. They are trying to access whether work is proceeding smoothly or some problem needs to be addressed.
For example, a report by abstractor of the number of abstracts completed for the month. If levels are reasonable (defined by manager and staff expertise), no problem. If level has dropped, would probably talk to abstractor (either directly or via abstract manager) to discover what the problem is.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Registry Manager
Location
CRO
Policies/Business Rules

Sensitivity

Trigger
Periodically
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.12 Remove Inappropriate Information

ID: 10.12

Description

Restricted information sometimes enters the registry as part of an otherwise needed record. This information must be removed.
Since these are frequently text fields, it's probably part of a text string that would be blanked out.
For Example: 'patient is HIV +' listed on a lab report or abstract about cancer would have to be removed.
Not everyone can make the decision to remove the data. Whoever notices the problem would need to notify the appropriate people and ask for a review. Seems likely that in most cases, the review would be nominal.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Any Registry Staff
Manager (unsure if registry manager, editor's manager, etc)
Field Staff

Location

CRO
Field L
Field H

Policies/Business Rules

Sensitivity

Trigger

Org Rep suspects patient information should not be kept

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.12.1 Notify Manager of Suspect Data

ID: 10.12.1

Description

Upon discovering information within a patient set or health record that the org rep believes should not be retained by the registry, they would have to inform someone with the power to delete the information if necessary.
I'm not sure what type of manager this would be. It could be the registry manager, the editor's manager, any super editor… It probably varies by registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Any Registry Staff

Location
CRO
Field L
Field H
Policies/Business Rules

Sensitivity

Trigger
Org Rep suspects patient information should not be kept
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.12.2 Respond to Review Request

ID: 10.12.2
Description
Reviewing suspect data and determining whether it should be deleted or retained; deleting data in the CRO if appropriate.
Manager calls up record or patient set specified and checks to see if the value in the specified data item should be retained or deleted.
If a manager has decided that information is inappropriate to be retained, it is removed from the CRO data stores.
When a request for a manager to review information has been logged, it should be put onto someone's task list.
DESIGN NOTE: If the manager decides that information should be deleted, it would be nice if when the manager makes the change, the request result is sent automatically.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Manager (I'm not sure which manager: registry mngr, editor's mngr, etc)
Location
CRO
Policies/Business Rules

Sensitivity

Trigger
Information review request received **and**
Manager has time
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.12.2.1 Review for Appropriateness

ID: 10.12.2.1
Description

Manager calls up record or patient set specified and checks to see if the value in the specified data item should be retained or deleted.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Manager

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Information review request received **and**
Manager has time

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

10.12.2.2 Remove Inappropriate Data

ID: 10.12.2.2

Description

If a manager has decided that information is inappropriate to be retained, it is removed from the Patient Set or Health and Supplemental Record Data stores as appropriate. (This would be the CRO data)

DESIGN NOTE: since they don't want to keep this, the HREC UPDATE or ACD stored would not want the 'old value'. The entity would be entirely automatically created, where Reason=Inappropriate information removed.

DESIGN NOTE: because of 10.12.2.3, it may be best to force the manager to select the text string they wish to delete so the computer can capture it.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Manager

Location

CRO

Policies/Business Rules

Sensitivity

Trigger

Information to be deleted **and**
Data in CRO

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

10.12.2.3 Modify Updates

ID: 10.12.2.3

Description
After the manager has deleted the information from the Patient Set or Health record, all past ACD or HREC updates to that field should be reviewed by the manager and the same string deleted.
DESIGN NOTE: if in 10.12.2.2, the computer captures the string being deleted, it could merely ask the manager if it's okay to remove the string from the following updates (manager hits okay instead of having to search and remove.)
DESIGN NOTE: during 16.0 synchronization tasks, any modifications made in the field that would be affected by the deletion of inappropriate information would need to be reviewed by the manager.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Manager

Location
CRO

Policies/Business Rules

Sensitivity

Trigger
Information to be deleted **and**
Updates exist

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

11.0 Maintain Security

ID: 11.0

Description
Maintaining the security of the Registry database and Registry Operations system (whatever it may be)
This includes maintaining the access information for registry staff as well as verifying access to the system, processes within registry operations and data accessed/modified during processing.
NOTE: we assume that the computer itself can be counted as an org rep and it is always 'logged in'.

Interested Registries
Interested:
Not Interested:

Local Procedures

HI, IA: have students working for them. Want to restrict people to the processes and information they need to do their job (fup staff, students, protect DMV, etc).
AT: students are given a subset of the registry data by a registry staff member.
LA: would like to be able to restrict what data people can see and what they can modify. More important what they can change vs what they can see. Process access restricted.
AT, NM, DT: can view anything, processes are restricted. Editors & managers can modify anything.
NM: may be screen or data item on screen that is limited
UT: no limits now to staff. Researches would be restricted to their own data.

Degree of Automation

Fully
Semi
Manual

Processor

Registry Manager
IT Manager
Computer

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Since this protects the data from un-authorized access and the data is so sensitive, these processes, especially 11.5 processes, must be well designed.

Trigger

New hire
Org rep role changes
Org rep leaves registry
Access is requested

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

11.1 Provide Training

ID: 11.1

Description

New hires to the registry staff must be trained in issues of sensitivity, data security and confidentiality.
This training may be on-line training, paper documents to read and sign or other, as determined by registry.
This would include legislation such as HIPAA as well as local policies.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi-manual
Manual

Processor
Registry Manager (this may be delegated, but since the manager hires people, they are ultimately responsible for making sure training occurs)
Location
Central Registry Office
Field Registry Staff Home (logged in)
Policies/Business Rules

Sensitivity

Trigger
New hire
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

11.2 Add Org Rep Access Info

ID: 11.2
Description
After training is completed, access information for the new org rep must be added to the system.
This includes creating an account and password for an org rep and setting all the access levels necessary for the registry. This includes process access as well as table and data item access, both read only and read/write access are expected.
DESIGN NOTE: would be nice to allow registry to create standard setting. They could start org rep with 'Standard A' and modify as necessary. This would hopefully shorten the time spent here. (Default would be roles the person can play; modifications would customize it by specific person.)
DESIGN NOTE: some users should only be able to log in during business hours when supervisors are available.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
IT Manager
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Training complete
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

11.3 Update Access Info

ID: 11.3

Description

Once an org rep has access information, if their role or responsibilities in the registry changes, the access information is updated to reflect this.
The authorization to do this comes from a manager.
This should just be setting changes. Access could be added or removed.
DESIGN NOTE: would be nice to allow registry to create standard setting. They could start org rep with 'Standard A' and modify as necessary. This would hopefully shorten the time spent here.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

IT Manager
Registry Manager

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Org rep role changes

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

11.4 Remove Org Rep from System

ID: 11.4

Description

When an org rep stops working for the registry, their account must be closed and access to the system revoked.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

IT Manager

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Org Rep leaves registry

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

11.5 Verify Access Level

ID: 11.5

Description

NOTE: most of these processes should be standard underpinnings of any system. We may not have to do much design/coding in order to obtain this.

When someone attempts to log in to the system, when they attempt to initiate a process (at any x.y level), and when they attempt to view or change data in the database, their ability to do so must be verified.
DESIGN NOTE: if x minutes of inactivity, want to log-out the person. X should be determined by registry by process during system set-up. They'd like at least 0-2 hours in 15 increments as possible choices. Some processes would be more forgiving than others. Also, some registries would rather security-lock the terminal (screen-saver lock) rather than kick the person out of the system entirely. NCS: not sure if the security-lock to terminal should be another process (11.5.5)
DESIGN NOTE: Many of the 10.7 tasks would interact with 11.5
DESIGN NOTE: Security of data item is complicated. They need to not only restrict who has access to a data item and what they can do (read vs write), but also what kind of changes can be made. For example, only select people can change vital status from dead to alive or back date a date of last contact value.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Since this protects the data from un-authorized access and the data is so sensitive, these processes must be well designed.

Trigger

Access is requested

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

11.5.1 Verify Log-in Attempt

ID: 11.5.1

Description

When a person or org rep attempts to log in to the registry system, their information must be verified.
Registries wish to track all attempts to access their system, successful or unsuccessful.
Searches account and password combinations for a valid match to account and password provided.
DESIGN NOTE: want to lockout the account if there are x number of failed log-in attempts. X should be selected by registry during system set-up. Registries may want to set time limit for how long lockout is in effect. (New Mexico).
DESIGN NOTE: some users should only be able to log in during business hours when supervisors are available.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor
Computer

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity
Since this protects the data from un-authorized access and the data is so sensitive, these processes must be well designed.

Trigger
Registry Operations Access is requested (system log-in)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

11.5.2 Verify Process Access

ID: 11.5.2

Description
Every time a process is called by an org rep, their access codes are checked to verify that they are cleared to run the process.
This is all process levels, not just the X.0

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor
Computer

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity
Since this protects the data from un-authorized access and the data is so sensitive, these processes must be well designed.

Trigger
Process is initiated

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

11.5.3 Verify Table or Data Item Access

ID: 11.5.3

Description
Every time an org rep attempts to view or modify data, their ability to do so is verified. They may have no access, read only access or read/write access. The access may be to an entire table or to data items within a table.

DESIGN NOTE: Registries noted that they need to restrict which tables a person can view (and potentially data items within a table, depending on the final structure). However they also said they wanted to restrict which patient sets a person can view. If this is determined to be a particular group of staff (students doing active follow-up) are only allowed to see those cases needed follow-up, best solution may be a data mart for that group of staff and disallow access to the main registry data.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Fully

Processor
Computer

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity
Since this protects the data from un-authorized access and the data is so sensitive, these processes must be well designed.

Trigger
Data item access is requested

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

11.5.4 Log-Off

ID: 11.5.4

Description
When an org rep chooses to or is forced to log off, the log-in status is changed.

This should include timed log-off (logged in account has been inactive for too long), system-wide log-off (system is being locked, everyone is kicked off, warning should have been given by 10.7.8, Notify Users to Log-off) and normal log-off (user chooses to log-off).

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

User requests log-off
Inactivity time limit reached
System requires log-off

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

11.6 Update Password

ID: 11.6

Description

A registry org rep must be able to change their own password (a shock to no one)

The IT manager may also change a password if the org rep requests them to do so. (ie forgotten password)

DESIGN NOTE: password change due trigger: The amount of time a password is valid for should be selected by registry during set-up of system. The workflow would notify org rep that 'password is expired'. Should probably have 5 day advance warning or similar.

DESIGN NOTE: want to keep password history so they can't reuse passwords. Want to force certain level of password complexity.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Org Rep (Seer registry)
IT Manager

Location

Central Registry Office
Field Laptop (freestanding)

Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Password change requested
Password change due

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.0 Generate Reports, Extracts, and Registry-Controlled Files

ID: 12.0

Description

NOTE: Likely the process to be most affected by HIPAA and similar privacy laws.
We aren't just collecting this information for "kicks," we are supposed to be a resource for CTC data and statistics. Therefore, once we have acquired the data, people/orgs can request CTC information from us. Requests for information must be valid and fillable, can be fulfilled with existing, standard or ad hoc methods, and problems from the requester must be addressed.
Information Sent: Reports: summaries of data, CTC listings, and statistical analyses. Extracts: Files which are sent out of the registry. They may be identified or de-identified and may require more than a simple data dump. Registry-Controlled Files: Files which are controlled by the registry. They may be identified or de-identified and may require more than a simple data dump.
This includes requests for internal and external use.
EXAMPLES of external requests: SEER submission (a standing request), John Q Public asks for survival rates for prostate cancer, Suzie Patient asks to see all the facility records a registry has received for her and the final patient set constructed from that information.
EXAMPLES of internal reports: metrics of CTCs submitted (what facility, who abstracted the CTC, how many errors made, time period from date of diagnosis); lists of patients with same SSN; CTCs w/ unknown site in patient set and primary site on DC. EXAMPLES of external reports: list of IDs in a submission (may also contain dx date for prioritizing); list of patients by physician, primary site and vital status. See "Info Needs Analysis.doc".
NOTE: While the registries put standard reports (CSR, annual reports) on their web site for public use (track number of hits, but not who – done via web master), they do not desire to have more extensive web access in the name of information requests. They feel its too easy to generate misleading data or data that doesn't really answer the requesters question so they prefer to deal with more detailed requests in person.
DESIGN NOTE: Registries need to be able to easily modify existing report/extract types and easily create new ones.
DESIGN NOTE: Registries would like to have a public web page (which they have now) attached to a reporting tool that can provide a limited set of reports (aggregate data with masked small cells.)
DESIGN NOTE: Would be nice to choose a reporting tool to be the SEER-DMS standard tool. That way the registries could share reports

easily. Would still need to connect with other tools in case the standard tool did not cover all reporting needs.

Interested Registries

Interested:

Not Interested:

Local Procedures

LA and DT would prefer that the field staff NOT do reporting. They want them to forward the request for a report to the central registry.

DT: this process is done by the research group, not the registry staff proper.

LA: this process is done by 2 different groups.

Some registries are interested in allowing physicians and facilities to sign into a secure web site (account and password provided by registry) and to then be able to access their own patient lists with some limited information (such as follow-up date). There would be no access to the main database, there would have to be a data store supported this functionality. ATL, NM and LA are not interested, they would prefer these requests still go through humans.

ATL: all reports are run by support staff (the IT group). They get lots of ad hoc reports.

Degree of Automation

Semi

Manual

Processor

Information Distribution Manager

Registry Manager and PI approve the requests and in some registries actual produce a fair number of the requests.

IT staff also produce requests

Registry Manager or PI may delegate some tasks (any registry staff)

Location

Central Registry Office

Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Warning! There are restrictions per report, extract or registry-controlled file re: who can receive what information. This needs to be determined for each report, extract or registry-controlled file.

Trigger

Request for information received **or**

Problem reported by requester

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

12.1 Receive Information Request

ID: 12.1

Description

As an information request is received, verifying that it is valid, determining if other documentation is needed (IRBs, collaboration agreements) and notifications to the requester about the status of their request.

All information requests enter the system here. Requests can be made by phone, letter, contract, or internally.

Requesters: NCI SEER, CDC, other organizations, reporting hospitals, other facilities, SEER registry (internal reports), doctors, patients, John Q. Public.

Interested Registries

Interested:
Not Interested:

Local Procedures

HI & DT require written requests.

Degree of Automation

Semi
Manual

Processor

Information Distribution Manager
Registry Manager
PI

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Information request received **or**
Request modified **or**
New documentation available **or**
Can't fulfill

Metrics

Frequency:
Volume: HI: 100ish a year; LA: 1 person handles 500 a year
Duration:
Quality/Error rate:

12.1.1 Evaluate Request Received and Create/Update Tracking Info

ID: 12.1.1

Description

Determining the validity of the request based on local, state and federal rules.
Trying to answer the question 'Is it legal to release this particular information to this particular requester?'
Some information can only be released to certain people/groups, some information can be released only with signed collaborator (confidentiality) agreement.
Update 'Report, Extract, Registry-Controlled File Request Tracking Information' to note status of request and appropriate reasons, documentation needed or received, etc.
Audit trail is available for changes to the information request or the information request problem.
If the request is to access analytical data, we will also need to find out the following in order to determine if the request is valid:

What the intent is
What the requester is using the information for – use of the data
Will it be published

Interested Registries

Interested:
Not Interested:

Local Procedures

Audit trails are desired by NM, IA, HI

Degree of Automation

Semi
Manual

Processor

Information Distribution Manager
Actual evaluation done by Registry Manager and PI

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Requests can come from a researcher, authorized facility reps, and/or other people, facilities or organizations.

Sensitivity

The release of confidential data (e.g. names) to a researcher requires Institutional Review Board (IRB) approval.
In California, a new law has been passed SB683(?) which restricts the release of data that can be used to identify individuals. The original goal was to prevent the data from being subpoenaed. However, the end result is still unclear. NCS believes this will mostly affect which information requests are approved, and not the actual mechanics. Talk with Dennis Deapen from LA if further questions occur.

Trigger

Information request received **or**
New documentation available **or**
Request modified **or**
Can't fulfill

Metrics

Frequency:
Volume:
Duration: HI: pretty quick; LA: usually seconds, possibly 30 minutes for complex issue
Quality/Error rate:

12.1.2 Notify Requester

ID: 12.1.2

Description

After evaluating the request, if the determination is made that the request is invalid, the requestor needs to be notified of the status and the cause. If the registry is unable to fulfill a valid requests at that time, the requester is notified of the status of the request and a projected time when the request would be fulfilled or what needs to change to make the request fulfillable (such as media requested).
DESIGN NOTE: LA and HI would love this to be as automated as possible so that the requester is aware that they have been heard.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual
Semi

Processor

Information Distribution Manager
(may be done by Registry Manager or PI)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger
Invalid request **or**
Can't fulfill

Metrics
Frequency: HI: 7-10 days after request received; LA: 3-7 days
Volume:
Duration:
Quality/Error rate:

12.1.3 Request Required Documentation

ID: 12.1.3

Description
Certain requests need to obtain IRB approval or have a signed Collaboration agreement before they can be considered valid.
The requester is notified as to what needs to be done and any necessary forms are sent.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Information Distribution Manager
(may be done by Registry Manager or PI)

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Need additional documentation

Metrics
Frequency:
Volume: HI: mostly IRBs are not needed, IRBs more likely for Special studies.
Duration:
Quality/Error rate:

12.2 Record Receipt of Documentation

ID: 12.2

Description
All IRB and Collaboration agreements need to be kept in case any should ask for them. These have legal ramifications for the requester.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Information Distribution Manager
(Clerical in nature)

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Documentation received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.3 Determine if Can Fulfill Request

ID: 12.3

Description

Answer the question 'Can the registry fill this request at this time?'
Look at the information we have available, the nature of the request and applicable rules to determine if we can even fulfill this request.
Examples of reasons why a request can't be fulfilled is because type of media not supported or data not yet available.
If request can not be fulfilled, then 'reason' is sent to requester (via 12.1.2).
If a request is not fillable, but is valid, the registries would retain the request information so when it becomes fillable, they can proceed.

Interested Registries

Interested:
Not Interested:

Local Procedures

HI: bases response on current information

Degree of Automation

Semi

Processor

Information Distribution Manager
(may be done by Registry Manager or PI)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Valid Request

Metrics

Frequency: LA: very frequent
Volume:
Duration:
Quality/Error rate:

12.4 Determine How to Meet Request

ID: 12.4

Description

Decide if the request can be met by an existing (already produced) report, extract or registry-controlled file, a Standard Report, Extract, or Registry-Controlled file format or if the request needs to be created from scratch (ah hoc).
What does the registry have at its disposal that might meet the need and what do they have to do to fulfill the request?

Interested Registries

Interested:
Not Interested:

Local Procedures

What a registry considers standard varies by registry. Registries may have the same name for a standard format or existing item, but include different information in these standards.
LA: Kathleen Danley sets up educational seminars for about ¼ of her requests. Also, seems that currently she is filling all non-standing requests with ad hoc methods.
HI: 25% are ad hoc (rest are SEER*Stat)

Degree of Automation

Manual

Processor

Information Distribution Manager
(may be done by Registry Manager or PI)
IT Staff

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Registry has to be able to add new 'standard' formats and classify existing report/extract/registry-controlled files as standard.

Sensitivity

Trigger

Can fulfill

Metrics

Frequency:
Volume:
Duration: LA: 0-15 min;
Quality/Error rate:

12.4.1 Determine if Existing Report/Extract/RCF Meets Request

ID: 12.4.1

Description

Looking at existing reports or extracts, as well as existing Registry-Controlled Files (things which have already been produced) to see if any of these will meet the Information Request.
If an existing report or extract is selected to meet an information request, the report or extract would simply need to be duplicated (e.g., re-printed or copied) and sent OR the URL could be sent
If an existing registry-controlled file is selected to meet the request, the requester may have to receive training and access to the file will have to be granted (account/password).
DESIGN NOTE: existing reports/extracts/RCFs that were produced on an ad hoc basis should have a synopsis attached to make this determination easier.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation
Manual
Processor
Information Distribution Manager
(may be done by Registry Manager or PI)
IT Staff
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules
This is an efficiency concern. The world won't end if they miss an existing item that would meet their needs, they'll just waste time recreating it.
Sensitivity

Trigger
Can fulfill
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

12.4.2 Determine if Standard Report/Extract/RCF Meets Request

ID: 12.4.2
Description
Looking at standard reports or extracts and Registry-Controlled Files (things which are produced regularly) to see if any of these will meet the Information Request.
If a standard report or extract is selected to meet an information request, the standard program(s) would have to be run and then sent.
If a standard registry-controlled file is selected to meet the request, the standard program(s) would have to be run, then the requester may have to receive training and access to the file will have to be granted (account/password).
DESIGN NOTE: it would be nice to have a synopsis attached to standard reports/extracts/RCFs to make this determination easier, but the fact that they are standard implies that they are regularly run and probably well known.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Manual
Processor
Information Distribution Manager
(may be done by Registry Manager or PI)
IT Staff
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

This is an efficiency issue. World won't end if standard is missed, they'll just waste time recreating it.
Some of the examples of standards are record layouts, some are applications that produce standard reports/extracts which we must interface with, and some are actually standard reports/extracts the registries produce now.

Sensitivity

Trigger

No (no existing report/extract/RCF, from 12.4.1)

Metrics

Frequency:
Volume: HI: 75% of requests are SEER*Prep/SEER*Stat type requests
Volume: LA: 10-15%
Duration:
Quality/Error rate:

12.5 Fulfill Request

ID: 12.5

Description

Produce the request fulfillment (if not existing) and send the report or extract or allow access to Registry-Controlled File and update the 'request fulfillment information'.
Provide necessary training and access information for registry-controlled files.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi
Manual

Processor

Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Determination complete **and (1 of 3)**
Request can be filled with existing report/extract/RCF **or**
Request can be filled with standard report/extract/RCF **or**
Ad-hoc report/extract/RCF required

(Follow-back Complete)

Metrics

Frequency:

Volume:
Duration: LA: for cancer cluster questions, may take up to 4 months to gather data (rare).
Quality/Error rate:

12.5.1 Produce & Send Report/Extract/RCF

ID: 12.5.1

Description

Creating a report/extract/ RCF that someone has requested and sending the report or extract.
If an existing report/extract/RCF meets a request then a new one does not be recreated, the old one just needs to be sent to the requester.
After the report/extract/ RCF is created, the tracking information needs to be updated so if the report is needed later it doesn't have to be recreated.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi
Manual

Processor

Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Outgoing extracts of data should be encrypted. This would also apply to reports in the form of Case listing. Aggregated data type reports would not have to be encrypted.
In reports, if a cell has a small number of entries, it is masked. Exact number varies by registry (HI: 4 or fewer. LA: 3 or fewer. IA: 5 or fewer)

Trigger

Determination complete
(Follow-back Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.1.1 Produce Ad -Hoc Report/Extract/RCF

ID: 12.5.1.1

Description

Create the Ad Hoc Report or Extract or Registry-Controlled File. Send the report or extract.
This be printed, electronically produced, web-enabled, etc.
Ad Hoc items that are used to fulfill many requests can become standard.
Store item produced for possible future use.

NOTE: may included back-and-forthing between registry and requester. If work needs to be done by registry, then requester, then more registry work. Should this be all considered as part of this process?

For reports, extracts or registry controlled files where patients or CTCs are specifically given (non-aggregate data), need to track which patients and CTCs were included in each fulfillment.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA: reviews data in depth before sending

Degree of Automation

Semi

Processor

Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

The release of confidential data (e.g. names) to a researcher requires Institutional Review Board (IRB) approval
If a report by cell (age x sex x county) has fewer than a given number, the cell must be masked. (* where *=X or fewer) This number seems to vary by registry. HI: 4 or fewer. LA: 3 or fewer. IA: 5 or fewer.

Trigger

Ad-hoc report/extract/RCF required
(Data problem resolved)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.1.2 Produce Standard Report/Extract/RCF

ID: 12.5.1.2

Description

Create the Standard Report or Extract or Registry-Controlled file. Send the report or extract.
This could be printed, electronically produced, web-enabled, etc.
For reports, extracts or registry controlled files where patients or CTCs are specifically given (non-aggregate data), need to track which patients and CTCs were included in each fulfillment.

Would be nice to include the following as standard reports/extracts (this includes reports, applications, record layouts, etc:

SEER Submissions (extract, record layout)
SEER*Stat (application: use to generate standard incidence, survival, mortality type reports. Scoppa – also CTC listings?)
SEER*Prep (application: produces SEER*Stat readable files)
Incidence Survival (reports)
NAACCR Submission Reports (report)
SEER Edits (application: used to generate edit reports – internal to registry)

NAACCR Format (Record layout)
Data Exchange (extract in NAACCR Format)
NCDB (extract in NAACCR Format)
NPCR (extract in NAACCR Format)
Annual Reports (report: varies by Registry)
Lost to Follow-Up (per Registry)
Number of Requests (Requested Information) for Reporting (report: from the Request File, which may be included in Working Data.)

Interested Registries

Interested:
Not Interested:

Local Procedures

A lot of them
Seattle is using the Web and a Virtual Private Network (VPN). Utah is using the Web.
Standard reports/extracts/registry-controlled files vary by registry.
Media available varies by registry.

Degree of Automation

Semi

Processor

Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Usually shred reports with patient information or keep it locked up
Generally don't send anything out of registry with patient identifiers on it
The release of confidential data (e.g. names) to a researcher requires Institutional Review Board (IRB) approval.
Note: Electronic transmission of reports must be secure. Printed reports sent certified mail.
If a report by cell (age x sex x county) has fewer than a given number, the cell must be masked. (* where *=X or fewer) This number seems to vary by registry. HI: 4 or fewer. LA: 3 or fewer. IA: 5 or fewer.

Trigger

Request can be filled with standard report/extract/RCF
(Data problem resolved)

Metrics

Frequency:
Volume:
Duration: HI: 1-2 hours usually
Duration: LA: via internet, about 20 minutes; send a book, about 2 hours; 50% 2-8 hours, and 50% 1-2 weeks (80 hours). Driven by amount of information asked for and their desire to review before sending.
Quality/Error rate:

12.5.1.3 Send Existing Report/Extract/RCF

ID: 12.5.1.3

Description

If an existing report or extract is selected to meet an information request, the report or extract would simply need to be duplicated (e.g., re-printed or copied) and sent or the URL could be sent

Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Manual
Processor
Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules
If sending an ad hoc item, probably should keep a count of how many times it's been used. Ad Hoc items that wind up being used frequently can become standard.
Also, if a problem is found by one requester, would be nice to know who else may need a corrected version.
Sensitivity

Trigger
Request can be filled with existing report/extract/RCF
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.1.4 Apply Follow-Back

ID: 12.5.1.4
Description
Results of follow back being applied to the registry data when the need for follow back was discovered while a report was being produced.
Editing will be done after updates completed
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Editor (most likely)
IDM
Other (whoever was producing the report)
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Follow-back Complete

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.2 Notify Requester re: RCF

ID: 12.5.2

Description
Tell the requester that the registry controlled file is available, how they access it (it's name, their account id and password) and any other pertinent information.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Manual
Semi

Processor
Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
RCF available **(possible and)**
Password received

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.3 Enable Access

ID: 12.5.3

Description
Allows the authorized researcher or organizational representative formal access to a registry-controlled file.
May include assigning an account id and password. May need to train researcher about how to access file or information in file before allowing access.
Information may be obtained from an extract registry-controlled file using a query-type program---analytic software package.

Interested Registries
Interested:
Not Interested:

Local Procedures
NM uses this process. Others do also, but with some variations.

Degree of Automation
Semi

Processor

IT Staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Training not required **or**
Training completed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.4 Train Requester

ID: 12.5.4

Description

A requester that is not familiar with the registry's system needs to be trained on how to access the RCF and extract pertinent information from it.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Information Distribution Manager
May also be done by Registry Manager or PI

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Training required **and**
Ready for training

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.5.5 Update Tracking with Selected IDs

ID: 12.5.5

Description

If a requester asked for an extract or registry controlled file, but is only using a selected sub-group, the registry may need to be informed of who is being used. (Similar to special studies)

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Processor
Information Distribution Manager
IT Staff
Location
Central Registry Office
Policies/Business Rules

Sensitivity

Trigger
Selected IDs Received
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

12.6 Identify Type of Problem

ID: 12.6
Description
Determine the type of problem that exists with the Report, Extract or registry controlled file was produced.
Direct problem to appropriate resolution task along with information request tracking ID
Possible problems include:
Data Problem (resolve data problem)
Format Problem (reproduce with new format)
Information request problem (misunderstood request, reprocess with corrected criteria)
Expanded Request (new request, process as usual. Collaborator agreements and IRB approval from prior request may possibly apply to this request as well.)
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Manual
Processor
Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)
Location
Central Registry Office
Field Laptop (freestanding)
Policies/Business Rules

Sensitivity

Trigger
Problem reported by requestor
Metrics
Frequency:

Volume: LA: because of intense review, they've only had 1 problem in several years (incorrectly stated request)
Volume: HI: 70ish, 5% data, 50-75% expanded or incorrectly stated requests. He tries to send more than asked for to reduce problems.
Duration:
Quality/Error rate:

12.7 Resolve Information Request Problem

ID: 12.7

Description

Determine the type of problem with the information request fulfillment and resolving accordingly.
Possible outcomes include confirmed format problems, confirmed data problem, corrected information request or expanded information request, any of these could have instructions to reproduce.
Resolution may also be 'Registry acknowledges the problem, but has no intention of fixing it.'
Includes handling both internal and external information request problems
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Need to modify request **or**
Can't change request **or**
Problem status changed **or**
Have resolution

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.7.1 Modify Request

ID: 12.7.1

Description

Format problems, expanded requests and incorrect (misunderstood) requests would also have to be modified.

Invalid requests may potentially be modified with the requester's permission.
After modifying the request, it is resubmitted to the system.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger
Need to modify request (from 12.6) **or**
Have resolution (from 12.8)

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

12.7.2 Notify Requester re: Issue Resolution

ID: 12.7.2

Description
The requester is notified as to the registry's response to their problem. The notification would include whether the registry agreed/disagreed with the problem, what action they intend to take, when a new fulfillment would be available if one is forthcoming.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Information Distribution Manager
IT Staff
May also be done by Registry Manager or PI
Registry Manager or PI may delegate the task (any registry staff)

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Can't change request **or**
Problem status changed **or**
Have resolution (from 12.8)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

12.8 Attempt to Resolve Data Problem

ID: 12.8

Description

Determine the nature of the "data problem" in relation to the Report, Extract or registry controlled file that was produced. For example, there could be a large amount of "unknown stages".
Verify data in relevant patient sets (visual editing) to see if there were mistakes made at registry.
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back requests as needed.
If follow-back results in new information, the Patient set is updated and/or the Health record update is made.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Follow-Back Clerk

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Possible data problem
(Follow-back complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.0 Confirm Receipt of Record

ID: 13.0

Description

This is the way records get from outside the system to inside the system. Includes receipt and tracking of submissions, parsing the submissions into individual records, and parsing each record into individual fields. Values are translated, coded and organized as much as possible into a form that makes sense inside the system.
Includes the receipt of paper records, including the broad screen, scanning and coding of such records.

Includes receipt of Registry created abstracts because you need to log it; later, these are screened in case what was identified as "reportable" has changed since the abstract was created. They are considered trusted health records.
Note: Seems likely that there will always been some paper reporting.
DESIGN NOTE: Need to be able to print abstracts at the end of this process. (CT loads abstracts electronically, and then prints them for the codes to review) I'm not sure if this is a report or just a 'print'.
DESIGN NOTE: depending on system speed for initial automated parts, would be nice to be able to scan incoming records as they enter the system to prioritize work. This is similar to the need for prioritization expressed by ATL after batch matching has been done. Would mostly be by year of diagnosis, but may also be by site, histology, year of birth. If records reach 4.0 quickly without much human intervention, could wait for priorities until then, but 1.0 is likely to slow down record processing.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA and DT consider this a CRO task only
IA Field staff get records sent to them, so need Field location ability.

Degree of Automation

Processor

IT staff
Computer
Office Assistant
File Room Clerk
Case finder/screener

Location

Central Registry Office
Field Laptop (freestanding)
NOTE: this would happen entirely at one or the other, you wouldn't switch locations mid process.

Policies/Business Rules

If the record comes from out of state, sometimes there is no recourse other than to accept the record as it arrived.
LA: facilities must maintain 3% or less error rate in their submissions or LA has right to tell them to change how they gather the information (hire registry, hire outside help, get more training, etc)

Sensitivity

Trigger

Data arrives at the registry (includes Health Records arrive on paper **and** Record arrives electronically)

Metrics

Frequency: DT: weekly submissions from abstractors, submissions from facilities every other month.
Volume:
Duration: HI: minutes to process a diskette. – download, convert to NAACCR, add to computer, initial matching.
Quality/Error rate:

13.1 Confirm Data Transmission

ID: 13.1

Description

Receive and verify clear transmission of data and information about the data has been received.
Notify the external hospital or other data source that the abstracts, other health record types, correction record or supplemental record were received and inform the originating source of any questions or problems regarding the transmission.
Also, check here for prior, or duplicate, submission with requisite notification. Duplicate submissions are deleted if found. The number of times a submission has been received is part of the submission information.
Track fulfillment of Data exchange agreements
DESIGN NOTE: Because we may have to remove health records that fail the broad screen from the archived submission, we may have to utilize a check digit in place of the actual non-reportable record in order to determine if a submission is a duplicate.
DESIGN NOTE: The registries sometimes receive encrypted file with encrypted fields within the file. (Name, SSN encrypted and entire file encrypted on top.) This step only HAS to un-encrypt the file, but may be easier to do both simultaneously.
Update 'Submission Data' with updated submission tracking information. (Typically, when we receive information, we also receive and/or create information about the information (e.g., format, type of file, number of records, etc.).
Update 'Information Acquisition Tracking Information' to reflect any general records requests that have been fulfilled. This includes health and supplemental requests. Would want to verify that what you received is what you asked for.
May need to be able to print list of records that have been received. (Whether this occurs here or as output of 'Confirm Electronic Data is Acceptable' is design)
DESIGN NOTE: may want to hold source messages until org rep chooses to send so they can be collected and sent in one burst.
DESIGN NOTE: when problems occur, not only does a message to the source need to be created, but the org rep processing the file should be notified about the nature and location of the problem (as applicable)
DESIGN NOTE: Need to allow for varying rejection criteria. This should be configurable by registry and possibly by facility.

Interested Registries

Interested:
Not Interested:

Local Procedures

NM: in effort to protect data, they remove it from FTP sites asap, they ask that all files be encrypted.

Degree of Automation

Semi

Processor

IT Staff
Computer

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Records arrives electronically

Metrics

Frequency:
Volume: LA: 2-3 duplicate submissions a month; 10-15 submissions rejected per year (usually due to a format change that hasn't been implemented). About 300 submissions (120 CTC/abstract; 80 correction; 80 fup; 15 passive fup)
Volume: HI: very few rejected, only reject if totally unreadable.
Volume: NJ: has large number of vendors and 12ish federal systems. Updates and versions of software changes without notice to registry. About 50-60% from MRS. This changes over time.
Duration:
Quality/Error rate:

13.2 Complete Pre-Processing of Electronic Records

ID: 13.2

Description

May have to un-encrypt file during this process. May have password protection. If password is incorrect or encryption algorithm has changed, this would cause a submission error.
NOTE: The registries sometimes receive encrypted file with encrypted fields within the file. (Name, SSN encrypted and entire file encrypted on top.) This step only HAS to un-encrypt the field, but may be easier to do both simultaneously.
DESIGN NOTE: need to allow for registry modifications to this process because of different record formats coming in from different sources. They change without notice to the registry and may have different valid codes for the fields included, as well as different file formats (layouts) or different applications (i.e excel spreadsheet).
If multiple record types are present in the same submission, the format must note this. The pre-processing would include verifying that all records within the file are identifiable as an expected record type and no anomalies are present.
DESIGN NOTE: Need to determine if this is a rules based or parameterized

Interested Registries

Interested:
Not Interested:

Local Procedures

NM: includes concatenating the DMV files, which typically come as 3 files and are concatenated and then run together.
NM: drops DWI information from DMV file as it is loaded into the system.
Seattle: has 1 organization sending records for multiple facilities in one file. They have to determine what the true source of each record is prior to converting the fields in the record. (hospital, clinic and Dr. office all in one file, but their records of the same type would potentially be different formats.)

Degree of Automation

Semi

Processor

IT staff
Computer

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Transmission confirmed

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.2.1 Determine if Pre-Processing Needed

ID: 13.2.1

Description

All electronic submissions need to be checked to see if any pre-processing needs to be done before the file can be read and what kinds. Processing could include decryption, file formatting, etc.
Also includes other pre-processing type issues (ATL HL-7 problem where records are split into 3 pieces and need to be recombined is an example)
Assess whether health record is from trusted source (such as our own abstracting tool, which already speaks our language), and if so indicate the health record as such. (The trusted health record can bypass '13.3.2 Convert Electronic Codes' if desired & designed as option.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

IT staff

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Transmission confirmed

Metrics

Frequency:
Volume: LA: 100% hospital abstracts from CNEXT (provided free by CA – NAACCR 9 headed to NAACCR 10)
Volume: HI: mostly in NAACCR format
Duration:
Quality/Error rate:

13.2.2 Do Pre-Processing

ID: 13.2.2

Description

The IT staff completes the pre-processing that is prescribed by the previous process. After pre-processing the submission is ready for processing.
If file format issues arise, the submission is saved until IT can contact the submitting facility with to clear up any formatting issues.
NOTE: The registries sometimes receive encrypted file with encrypted fields within the file. (Name, SSN encrypted and entire file encrypted on top.) This step only HAS to un-encrypt fields, but may be easier to do both simultaneously in 'Confirm Data Transmission'.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
IT staff
Computer

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger
Pre-processing needed

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

13.3 Convert Electronic Records to Standard Format

ID: 13.3

Description
Determining if each record is acceptable and converting the data to registry standards.
This is done for all non registry-generated electronic Health Records, such as hospital-created abstracts.
This process changes physical storage format by taking input data and changing it to local standards for formatting.
Examples include converting codes for gender, codes for race, changing the date format. May also address default data issues, such as a default is set to zero and it should converted to be nine.
This is a matter of knowing the format of incoming data, and converting it to a standardized, internal form (e.g., some file formats will represent Male gender as 'M', others '1', etc.).
If unexpected values are discovered (format used to send data should have been confirmed in 13.2, Confirm Data is Valid), they would be resolved using the Follow-back process. This is a more detailed look at the data at the individual item level.

Interested Registries
Interested:
Not Interested:

Local Procedures
LA: NAACCR is standard incoming format. Changes yearly or less: depends on NAACCR

Degree of Automation
Fully

Processor
Computerized

Location
Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

No pre-processing required **or**
Ready for processing
(Edit Complete)

Metrics

Frequency:
Volume: HI: 7500-8000 documents for 5500 CTCs; 500-600 per month; NJ 110K-120K per year (about 45K CTCs); 400-600 new CTCs per month
Duration:
Quality/Error rate:

13.3.1 Confirm Electronic Data is Acceptable

ID: 13.3.1

Description

Check that the data (electronic) in each record is uncorrupted, that fields haven't been dropped, and that coded fields use legitimate codes.
This includes an integrity check, as well as the type of editing that occurs in "17.1 Compare Individual Value to Rules" (computer field editing).
This is a check for wide-spread errors and field quality. It is not checking for consistency across fields. (i.e. race code not filled in for any record in file, entire record is out of sync with record layout, etc). Smaller errors can be handled in follow-back (i.e. 1 record is missing race).
File wide checks should be handled first: examples include ICD-9 site field must start with 'C'; zip code must be numeric; NAACCR version number must be present.
If the data is determined to be invalid, the record is sent back for resubmission.
Need to allow for a submission being rejected because too many records are considered unacceptable. Not all registries will use this.
DESIGN NOTE: may want to hold source messages until org rep chooses to send so they can be collected and sent in one burst.
DESIGN NOTE: when problems occur, not only does a message to the source need to be created, but the org rep processing the file should be notified about the nature and location of the problem (as applicable)
DESIGN NOTE: to aid in determining if a file or record is acceptable, this process needs to count how many errors are found. Also needs to take into account the severity of the errors found.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA: no standard for how many records can be problematic prior to submission rejections. They go by feel and type of problem (Scared they won't get a re-submission)
HI: doesn't reject submissions. (again, scared it won't come back)
IA: rejects submission if 1 record fails.
NM: probably reject entire supplemental file if records fail. For health data, they are more relaxed. Depends on how many records are affected and how likely it is a re-submission will occur (human judgment call).

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Ready for processing **or**
No pre-processing required
(Edit completed)

Metrics

Frequency:
Volume:
Duration: LA: about an hour. If problems found, time becomes longer depending on how hard it is to find the problem.
Quality/Error rate:

13.3.2 Convert Electronic Codes

ID: 13.3.2

Description

When a record is received, the codes and text must be converted to some established standard. The coding system that the information is received in must be translated into the system that the registry prefers. The converted codes relate to the record and are maintained with the record if the record passes the SEER &/or Local &/or Special Study Reportability.
In new world, when 'editing', must also ensure proper codes are used. There is demographic coding, medical coding and geographical coding. For example: Race - white converts to 1; is an example of demographic coding
Medical coding example: Breast Cancer/Tumor = ICDO3 codes C50.0 – C50.9
Geographical coding example: Maryland Montgomery County = FIPS code 24/031
Much of the conversion should be based on pre-processing from 13.2
DESIGN NOTE: for conversion of codes and selection of keywords which can not be automated, registries would manually do those tasks while screening as needed. The balance of these tasks would be done during the Consolidate processes or Conduct Abstracting, as appropriate. Information received at the central registry does not have to be structured as an Abstract before being consolidated.
DESIGN NOTE: While this is shown as happening before 13.4, these processes are to a large extent interchangeable. The less automated 13.3.2 is, the more efficient it is to do 13.4 first.

Interested Registries

Interested:
Not Interested:

Local Procedures

The NL BPM reflects that trusted health records do not have to enter this process. However, the NP models do NOT show this. While it is true that trusted health records should not need to be converted, it is equally true that sending them through this process won't hurt anything and some registries don't trust any records.
Things which qualify as Trusted Health Record vary by registry and are entirely dependent on registry policy. Possible examples are data from other SEER registries, data in NAACCR format from organizations where the registry feels the abstractors are skilled, etc.

DESIGN NOTE: may wish to allow option that submission is trusted and can bypass this task.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Data is acceptable
(Edit completed)
(Follow-back Complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.3.2.1 Convert Data to Local Registry Standards

ID: 13.3.2.1 and 13.8.2.1

Description

This is done for non registry-generated Health Records, such as hospital-created abstracts.
This process changes physical storage format by taking input data and changing it to local standards for formatting.
Examples include converting codes for gender, codes for race, changing the date format. May also address default data issues, such as a default is set to zero and it should converted to be nine.
This is a matter of knowing the format of incoming data, and converting it to a standardized, internal form (e.g., some file formats will represent Male gender as 'M', others '1', etc.).
If unexpected values are discovered (format used to send data should have been confirmed in 13.3.1, Confirm Electronic Data is Acceptable OR 13.6 Confirm Paper Data), they would be resolved using the Follow-back process. This is a more detailed look at the data at the individual item level.

Interested Registries

Interested:
Not Interested:

Local Procedures

DT, UT, CA HI, IA: mostly getting things in NAACCR format. NAACCR version is part of record. (IA from all but 1 large facility) This provides all needed info for layout and item formats. NM gets some in PC Dash (stable layout/formats), some NAACCR and some random.
For the 'other' vendor record submissions, the record layout and individual data item formats frequently change. They store this info, currently on paper.
The source submission is archived – totally untouched records. For each record, the 'original' black part has recodes/conversions which are not subject to change and are exact (one to one value change, no human intervention, not subject to modified interpretations) as well as original values that did not need to be modified. This recoding is almost

immediate. The 'converted' blue part contains data items which repeat due to the need for multiple coding schemes with human intervention (i.e. site, hist, beh, grade, treatment, eod). Track all changes so that need for intervention or new training can be determined.

Degree of Automation

Fully

Processor

Computer

Location

Central registry
Field Laptop (freestanding) 13.8.2.1

Policies/Business Rules

Sensitivity

Trigger

Data is acceptable **or**
Data is entered

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.3.2.2 Convert ICD Codes & Decipher Disease Text

ID: 13.3.2.2 and 13.8.2.2

Description

All ICD codes will be converted -- not just those in the neoplasms range. Converting diagnosis codes (and death codes in the case of death certificates or autopsy reports).
This process also culls disease text for key words.
Not converting all the codes received, e.g. country codes. This would be done in 'Convert Data to Local Registry Standards'.
This process doesn't apply for Registry-created abstracts. It is assumed the abstractors used the correct codes.
Medical coding may be occurring here. Corresponds to Create Abstract. If not done in these early tasks, must occur during 4.1.5, 4.1.6, 4.1.7, 4.1.8: Auto Create CTC and Treatment Information OR during 4.3.2, 4.3.3, 4.4.2, 4.4.3: Consolidate CTC and Treatment Information.

Design Consideration

From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. However, do need to allow coders to type in information, possibly with auto complete (some think it is faster than searching the list).
If this is a manual process (not the computer), this would probably be more efficiently done after an initial visual screen (4.0 tasks). The more automated, the better.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central registry
Field Laptop (freestanding) 13.8.2.1

Policies/Business Rules

Sensitivity

Trigger

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.3.2.3 Determine Residency

ID: 13.3.2.3 and 13.8.2.3

Description

Establish residency of patient at date of diagnosis. This includes, at a minimum, the actual state of residence and the county of residence.
Note: the indicator of whether the patient is within the registry's domain is set during the screening
Note: Does not operate on DC's, pathology reports or disease indexes because these records don't have address at diagnosis (the "residency" concept just isn't applicable).
Registry has to review the record to determine if patient resides in registry's domain or if they must pass the record along to another Registry or organization if not in the Registry's domain.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central registry
Field Laptop (freestanding) 13.8.2.1

Policies/Business Rules

Sensitivity

Trigger

Metrics

Frequency:
Volume: LA: abstracts, DC – 99% have residency; path reports - almost none; radiation therapy – almost none, have to follow-back to get address
Volume: HI: abstracts – 100%, very few others. 1 lab combines billing and dx (large lab)
Duration:
Quality/Error rate:

13.3.2.4 Convert Other Codes and Other Text

ID: 13.3.2.4 and 13.8.2.4

Description

Converting variables collected specifically for a special study into the registry selected coding scheme.
Also would select text words and phrases that were important to the special study.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA: doesn't do this.
HI: 10-20 items now, it's growing.

Degree of Automation

Fully

Processor

Computer

Location

Central registry
Field Laptop (freestanding) 13.8.2.1

Policies/Business Rules

Sensitivity

Trigger

Metrics

Frequency:
Volume: HI: 15-20 items
Duration:
Quality/Error rate:

13.3.2.5 Send Update Notification

ID: 13.3.2.5 and 13.8.2.4

Description

Notifies the source of a health record about changes made to that record. This allows the source to disagree with a change or apply it to their own data.
DESIGN NOTE: These changes should probably be queued and send in one large notice rather than continual notices.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central registry
Field Laptop (freestanding) 13.8.2.1

Policies/Business Rules

Sensitivity

Trigger

Update exists **and**
Notification desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.4 Eliminate Duplicates & Assign Census Tract

ID: 13.4

Description

An up-front, automated check to throw out true duplicate records before they enter the Registry's data. Could be facility or supplemental records being checked. Trying to save time by not re-processing records. See '13.4.1 Check for Duplicate records' for more information.
Census tracting will also be done for each record at this point.
DESIGN NOTE: While this is shown as happening after 13.3.2, these processes are to a large extent interchangeable. The less automated 13.3.2 is, the more efficient it is to do 13.4 first.
LA would like more duplicates caught at this point.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Data is acceptable & standardized **or**
Data is acceptable & in electronic form **or**
Have address at Dx

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.4.1 Check for Duplicate Records

ID: 13.4.1

Description

An up-front, automated check to throw out true duplicate records before they enter the Registry's data. Could be facility or supplemental records being checked. Trying to save time by not re-processing records.
Duplicate facility records may result in notification to facility to please stop sending duplicates. Not true for all record types or all sources.
Assumption: previously-submitted – no "match" required
Does not require that codes have been converted in order to check for duplicate facility especially if the converted fields are additional fields.
This could be records from previous submissions or records within the same submission that are duplicated. (Same record included twice in one submission needs to be caught here.)

Record ID is added ('health record id' or 'supplemental record id') is added and record is stored in Health and Supplemental Record Data.

Design Consideration

Some registries have a mechanism for determining patient-CTC-facility match here and reject that level of duplicate. Currently, ATL has an exact match on 10 fields, NCCC creates a key from several fields and if the key matches, they consider it exact.

We were planning on only catching byte-for-byte matches here and allowing the rest of the records to travel through the system and be captured in consolidation. We felt that information was being lost if changes were made to fields other than the key fields.

As a compromise between checking exactly and losing data changes, we could check on 10 fields (or whatever). If a match is found, notify the facility of duplicate record (if desired). Then check for byte-to byte match. If so, discard record, if not, note the patient set that the matching record is linked to and send directly into consolidation. Highlight the differences to focus the org rep's attention.

In the BOM, if an exact duplicate record is found, a new source submission includes… or follow-back response includes… relationship is found, not a new health record occurrence.

Would be nice if the key fields in question were configurable by registry.

Interested Registries

Interested:

Not Interested:

Local Procedures

LA: this is manual for them. They find these during visual editing. They use 12 fields to find possible dups.

HI: currently comparing entire record visually

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office

Policies/Business Rules

Notification of duplicate records should really only go out for health records of the non-list type.

May want to design a by-pass for this process for the record types listed below.

Death certificate, death lists and facility list type records used for quality control (like disease index, discharge list, surgery log) would not generate duplicate notifications in the event of exact duplicates. You might want to check for them, but not 'complain' if you have them. List type health records are usually being used to verify that no cancer/tumor/cases have fallen through the cracks and they again want the entire list.

Checking for duplicate supplemental records is not a requirement, but a 'nice to have'. Supplemental records are usually coming as a complete file which the registry has purchased.

Probably wouldn't bother to send duplicate notification to out-of-state source. These are usually 'take what you get' sources and there isn't a point to notifying them. However, no reason to not allow the ability.

Sensitivity

Trigger

Data is acceptable & standardized **or**
Data is acceptable & in electronic form

Metrics

Frequency:
Volume: LA: about 5% of records received are duplicates
Volume: HI: not uncommon (retransmission accidentally)
Duration:
Quality/Error rate:

13.4.2 Assign Census Tract

ID: 13.4.2

Description

Assign census tract code based on address at time of diagnosis (per CTC) and date of diagnosis.
NOTE: The boundaries of census tracts are subject to change every 10 years.
DESIGN NOTE: This is currently done as out-sourced batch. Would be nice to allow the capability for in-line processing (in case information is already in registry). However, there may be manual resource constraints in making the assignment. If it is determined that computer could accommodate the assignment rules, no reason this couldn't be in-line. Registries will only do this task here if it is automated.

Interested Registries

Interested:
Not Interested:

Local Procedures

NCCC, LA - There may be a requirement to obtain more than one census code because the codes change every 10 years.
Some registries periodically send batches of addresses to an outside organization, which assigns a census tract for each. (Must add dummy addresses to this batch to prevent it from being strictly CTC data.)
Some registries (e.g. NM, DT) do the mapping in-house.
Some registries have found that maintaining this was headache producing. They have decided that outsourcing this task (in batch mode) went more smoothly.
LA: would do this now if possible. Currently not getting the data for at least 3 months.
HI: would do this now, they do it fairly early currently.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Have address at diagnosis

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.4.3 Assign Record ID

ID: 13.4.3

Description

IDs assigned to the received records to facility tracking information flowing through the system, tracing source records of patient sets, etc.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office
Field Laptop (freestanding) paper

Policies/Business Rules

Sensitivity

Trigger

Record is ready to be saved.

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.5 Confirm All Records Received

ID: 13.5

Description

This process confirms to the sender of the records (paper) that all records have been received. Before confirmation is given, the record count is compared to the actual numbers and types of records for verification.
Tracking information is also updated to show receipt of record.
If any widespread errors are found during this process, notification is given back to the sender.
Track fulfillment of Data exchange agreements

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Office Assistant

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Health Records arrive on paper

Metrics

Frequency:

Volume: LA: only path reports are on paper (20,000 reports kept), moving toward e-path (3-4 hospitals have changed)
Volume: HI: military hospital is paper: 900 CTCs per year, 10%ish
Duration:
Quality/Error rate:

13.6 Confirm Paper Data

ID: 13.6

Description

Check to see if the paper record is of interest and for those that are, verify that the data on each record is complete and that coded fields use legitimate codes.
This includes a broad screen akin to 1.1
If the data is determined to be invalid, the record is sent back for resubmission.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Manual

Processor

Case Finder/Screener

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Package OK

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.6.1 Determine Potential CTC and Special Study

ID: 13.6.1

Description

Because the data was received on paper and it takes significant effort to convert, code and scan such a record, the registry determines that the record is of interest to them before proceeding with these tasks.
This is akin to the broad screen in 1.1, however, records which fail this screen are typically not used for follow-up (since they would have to be coded to do so), they are just destroyed.

Interested Registries

Interested:
Not Interested:

Local Procedures

NJ wants to match here before doing data entry.

Degree of Automation

Manual

Processor

Case finder/Screener

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger
Package OK

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

13.6.2 Confirm Paper Data is Acceptable

ID: 13.6.2

Description
After it is determined that a paper record is of interest, the record is reviewed to verify that all necessary information is available.
If the data is determined to be invalid, the record is sent back for resubmission.
Minor problems can be corrected via follow-back
Need to allow for a submission being rejected because too many records are considered unacceptable. Not all registries will use this.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Manual

Processor
Case finder/Screener

Location
Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules
LA: no standard for how many records can be problematic prior to submission rejections. They go by feel and type of problem (Scared they won't get a re-submission)
HI: doesn't reject submissions. (again, scared it won't come back)
IA:

Sensitivity

Trigger
Potential CTC/ special study

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

13.6.3 Conduct Paper-based Passive Follow-Up

ID: 13.6.3

Description
For those paper records that have been determined to be non-reportable (i.e. registry has no legal right to keep), the registry may still desire to do passive follow-up.

They search for the patient in the DB, if found they determine if the current record has better follow-up, if so, they update the follow-up information in the patient set and create the passive follow-up record.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries may choose not to do this because of the staff time it takes up.

Degree of Automation

Semi

Processor

Case finder/Screener

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Non-reportable record **and**
Passive follow-up desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.6.3.1 Search for Follow-Up Data

ID: 13.6.3.1

Description

For those paper records that have been determined to be non-reportable (i.e. registry has no legal right to keep), the registry still desires to do passive follow-up. They are searching for better follow-up.
This process includes a search of the database for the patient listed in the record. (see 4.1.1)

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries may choose not to do this because of the staff time it takes up.

Degree of Automation

Semi

Processor

Case finder/Screener

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Non-reportable record **and**
Passive follow-up desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.6.3.2 Select Best Value for Follow-Up

ID: 13.6.3.2

Description

Given that a paper record is not reportable (failed broad screen, not legal to keep), but it does match a patient in the current database, the registry would like to update follow-up information if possible.
The date of patient contact from the record is compared to the last follow-up date in the patient set and the best value is selected.
Only certain information from/about the record may be kept at this point and only for tracking purposes. When better follow-up is received, the registry may choose to discard the information about these records.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Case Finder/Screener

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Patient match found

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.6.3.3 Create Passive FUP Record

ID: 13.6.3.3

Description

Given that a paper record is not reportable (failed broad screen, not legal to keep), but it matches a patient in the current database and has better follow-up information, the registry would like to retain a limited amount of information from the record and assign it a health record id.
First the relevant information must be entered by a person into the system since this is a paper record. Then a health record ID must be assigned, probably by the computer. Then the record is added to the Health and Supplemental Record Data.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Case Finder/Screener

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Follow-up data updated

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.7 Scan Data

ID: 13.7

Description

All paper health records need to scanned and archived. After scanning the record, the paper version should be destroyed.
This preserves an original copy of the data as it was received, but the computer is not able to process this image accurately (hence the need for '3.8.1 Enter Data'

Interested Registries

Interested:
Not Interested:

Local Procedures

NJ: tried this before and found it to be problematic. Are willing to try again. They feel problem may have been technology was not advanced enough at the time. They also believe it is easier to pick a time and scan records from that point forward and problematic to scan archived materials – you have to enter information by hand for indexing.

Degree of Automation

Semi

Processor

File Room Clerk

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Health record of interest **and**
Data acceptable

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.8 Convert Paper Data to Standard Format

ID: 13.8

Description

This is done for all non registry-generated paper Health Records, such as hospital-created abstracts and path reports. They must be keyed and converted in registry standard format.
If unexpected values are discovered (format used to send data should have been confirmed in 13.6, Confirm Paper Data), they would be resolved using the Follow-back process. This is a more detailed look at the data at the individual item level.
This would include changing physical data such as newspaper and other paper media into electronic versions. (data entry and conversion)
DESIGN NOTE: to aid in determining if a file or record is acceptable, this process needs to count how many errors are found. Also needs to take into account the severity of the errors found.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi
Fully

Processor

Coder
Fully

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Health record of interest **and**
Data acceptable
(Edit complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.8.1 Enter Data

ID: 13.8.1

Description

The keying of health information received via paper into the system.
This keying process should enter the data as it is shown on the paper, conversion occurs later. This preserves an accurate record of the data's journey through the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Coder

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Health record of interest **and**
Data acceptable
(Edit complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

13.8.2 Convert Codes for Paper Records

ID: 13.8.2

Description

This process changes the storage format of some data items by changing it to local standards.
Examples include converting codes for gender, codes for race, changing the date format. May also address default data issues, such as a default is set to zero and it should converted to be nine.
This is a matter of knowing the format of incoming data, and converting it to a standardized, internal form (e.g., some file formats will represent Male gender as 'M', others '1', etc.).
This specifically applies to paper records which have been entered in electronic form.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computer

Location

Central Registry Office
Field Laptop (freestanding)

Policies/Business Rules

Sensitivity

Trigger

Data is entered
(Follow-back Complete)
(Edit complete)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

14.0 Update Data Source

ID: 14.0

Description

Currently using Registry view, not facility view. HIPAA intention seems to be allowing this to continue.
Determine changes that have been made (Original Abstract or Last Update sent vs. Patient Set registry view) and notify the data source of the updates they are allowed to receive.
This is an opportunity to supply facilities with the registry's unique patient number.
1st time this is done - compare the Original Abstract to the current Patient Set to determine if there are any updates made since the Original Abstract came in. Changes at facility view would be corrections, changes at registry view would be better information from another source or registry determined best value. (registry disagrees with facility)
Subsequent times - Compare what you last sent them (Last Patient Set Snapshot for Facility) and differences already sent to the current Patient Set. Shouldn't modify facility view with information they are allowed to know until they confirm that they have accepted the update.

New change: in current registry patient set, not in differences or current facility view patient set (or original abstract); send to facility, store difference

Old change, accepted: in current facility view patient set and in differences; do not resend.

Old change, unknown if rejected: not in current facility view patient set, in differences; set policy by registry, may wish to resend x number of times before giving up.

Alternatively, compare Current Patient Set to collection of differences and Original Abstract. Would only have the opportunity to send difference once.

DESIGN NOTE: This process can be done proactively each time a patient set status is set to submissible or as a batch job on all submissible patients. This may be a situation where modularity has to be provided so registries can choose. Either way, would probably hold all differences notifications until a selected 'send' date. See *Local Procedures.*

DESIGN NOTE: LA mentioned that they send follow-up information to the facilities prior to asking the facilities for follow-up information for the registry. It would be nice if work flow could tie 7.2.1 decision to contact facility (or 7.2.2 generating the letter for the facility) to 14.0.

DESIGN NOTE: This particular implementation may not be the best. It may be better to select the ACD and HRec Updates for the facility views in question and send notification of those. (The BOM appears to represent that.)

Interested Registries

Interested:
Not Interested:

Local Procedures

Optional to registries whether or not they run this process. Optional within registry as to which sources they do this for, some data sources are not interested in registry's belief of best data.
UT: runs this monthly because all the facilities use their database system. It is possible that not all facilities will want to change over to the new system. They are currently sending Registry view information back. (includes follow-up and DC information.) not source of info.
HI: sends follow-up date, registry id, name, dob, treatment, follow-up source, address, site, histology, etc. Would like a web based reporting tool for facilities so they could generate some information themselves.
NM, UT, HI, IA send best information possible, but not the source of that information.

LA: mostly returning follow-up information. (not source of follow-up) Would only return more that follow-up if trying to replace a facility DB that had crashed. Would use the facility view.
DT: sends list of dead people to source. Also sends follow-up information. Sends abstractor report- for each patient/ctc, a subset of the PAT and CTC attributes. (registry view). Only sends treatment if asked, and used facility view.
NM: provides diagnosis facility to those facilities treating the patient for the same CTC.
AT: provides FUP and DC information only.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Not all facilities can receive all patient information. Depending on local law, some facilities may only be able to receive data from selected other facilities, but this varies by registry and facility.
Not all facilities are interested in getting this kind of information.
Primarily for hospitals that have their own cancer registrar.

Sensitivity

DESIGN NOTE: See design note in BOM Supplemental records. They need to be able to tell that certain data item values are restricted.
Possible solution okay-ed by SMEs: put all incoming info into view. Then put sensitivity flag on view. In 14.0, computer would have to determine if information was obtained from any non-sensitive source. Second solution: add flags to data items this affects in the registry view that note whether value is restricted or not.

Trigger

Periodically **and**
Patient set status = consolidated (or better)
LA: Tries to send back follow-up information to a facility before requesting follow-up information from that facility.

Metrics

Frequency: LA & HI: Quarterly
Volume: HI: 20 hospitals; LA: 70 hospitals
Duration:
Quality/Error rate:

14.1 Select CTCs from Facility

ID: 14.1

Description

For each facility (for the ones you care to do this for), select all CTC's from that particular facility.
Based on facility view and CTC set combinations.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Periodically **and**
Patient set status = consolidated (or better)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

14.2 Compare Current Selected View to Snapshot of Selected View of Patient Set

ID: 14.2

Description

After selecting all the CTCs from a particular facility, they need to be compared to their snapshot to find differences.
The first time this process is ran on an individual patient, the snapshot is the abstract that the facility sent in.

Selected view is usually the Registry view. However, the computer will need to verify that information in the registry view was obtained from a non-restricted source. If the data item value only can be found in a restricted view, then the facility view data item value must be used. For example, in IA if current address in the registry view is found in DMV view only, the facility view current address should be sent.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

CTCs found for facility

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

14.3 Compare Differences to Previously Sent Differences

ID: 14.3

Description

So the registry is not resending differences that were found the last time this check was made, the differences should be compared to the differences that were already sent to the facility.

DESIGN NOTE: registry may wish to send differences more than one time if the facility does not accept the difference. Should be an option.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Differences found

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

14.4 Notify Facility

ID: 14.4

Description

After discovering any differences between the registry's records and a facility's records, the facility needs to be notified of these differences. However, what the registry is permitted to tell to a facility is dictated by state and local rules.

DESIGN NOTE: If the facility in question receives complete patient set information from the registry, should give options of record layout. ATL and SEA mentioned they would send in NAACCR format).

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

New differences found **or**
Differences found & Facility receives patient set

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

14.5 Track Differences Sent

ID: 14.5

Description

After sending the differences are sent to a particular facility, the tracking information should be updated so the same information is not resent.

DESIGN NOTE: if the registry wishes to send changes multiple times if they are not accepted the first time, would need to track how many times a change has been sent.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

New differences found

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

14.6 Update Snapshot

ID: 14.6

Description

After sending the differences to the facility, the snapshot that was used in the comparison is updated to the current version.

This doesn't need to happen if there weren't any differences, but it doesn't hurt anything if it does happen

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Differences found

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

14.7 Track Facility Acceptance

ID: 14.7

Description

Updates the tracking of facility acceptance of an update notification. Tracks the facility acceptance of a health record update and ACD that they have been notified of.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Facility acceptance received

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

16.0 Exchange Registry Data

ID: 16.0

Description

The exchange of data – patient data as well as task and tracking data – between the CRO data stores and the Laptop computers, aka computers that must function independently of the central registry computer.
Data stores affected include Patient Set, Health and Supplemental Record Data, Follow-Back Tracking Information; Follow-up Tracking Information, Abstract Facility Leads and Edit Issue Tracking Information.
Not all registries will wish to use all data exchanges.
DESIGN NOTE: seems more than likely that the registries will not want a Field data dump to immediately affect registry data (especially patient sets). They would likely want to verify the data suffered no corruption during transfer. Patients would probable have to be consolidated by an editor at the CRO.

DESIGN NOTE: This represents sync between free standing data (laptop) and CRO, which may happen over serial port in CRO or may happen over encrypted phone line external to office. True problem is whether you are crossing the firewall or already behind it.
DESIGN NOTE: If the connection is external to CRO (outside the firewall), all data would need to be encrypted when leaving its source and unencrypted upon entering the 16.x process.

DESIGN NOTE: Communication between a connected computer and the CRO computer (encrypted over phone line, etc) would have to occur during whatever process being run. (10.0 being done by manager at home would have to communicate during 10.0)

DESIGN NOTE: Would need to check for Patient sets or Health records updated within 10.12 against updates made in the field. Any updates after a 10.12 modification to the same data item should be reviewed by a manager before being permanently stored (update may need to be modified as in 10.12.2.3)

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

(Actually, this is happening AT the CRO, but the Field Laptop or the Staff's home computer must be connected at the time)

CRO

Field Laptop (freestanding)

Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Probably need secure hand shakes and so on to verify that the computer trying to connect is valid.

Trigger

Update desired

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

16.1.1 Update Field Patient Sets

ID: 16.1.1

Description

Updating the patient set data stored on a laptop or a home computer with patient set data in the CRO.

Likely that only selected subset of patients or patient views would be needed (ie those patients who had encounters at a mobile abstractor's hospital).

Interested Registries

Interested:

Not Interested:

Local Procedures

Not all registries are interested in provided patient set data to their mobile staff.

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO

Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
Field patient update desired

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

16.1.2 Update CRO Patient Sets

ID: 16.1.2

Description
Updating the patient set data stored in the CRO with the newly obtained/modified patient set data stored on a laptop or a home computer.
Likely that only selected subset of patients or patient views would be found on the laptop.
DESIGN NOTE: Registries will most likely want this information to go through 4.0 consolidation before becoming permanently attached to the patient set information. This will need to go into some temporary holding area.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi

Processor
Field Staff (either a mobile abstractor type or a manager from home)

Location
CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
CRO patient update desired

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

16.2.1 Update Field Record Data

ID: 16.2.1

Description
Updating the health record data stored in the on a laptop or a home computer from the CRO data.

This includes any health records that the CRO believes the field staff should have. Could be records to aid in abstracting or in follow-back, etc.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Field record update desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

16.2.2 Update CRO Record Data

ID: 16.2.2

Description

Updating the health record data and tracking information stored in the CRO with the newly obtained/modified health record data stored on a laptop or a home computer.

This would include abstracts created by the field staff, health records such as path reports gathered by the staff, non-reportable reasons for records they were researching, and tracking information for any updates made to health records.

Not all registries feel that health records obtained in the field and used to create abstracts need to be sent to the CRO. However, path reports gathered from a lab would probably need to be provided to the CRO.

DESIGN NOTE: Most likely the registries will want this data to go through 13.0 for confirmation before it is added permanently to the CRO data. It will need to be temporarily stored.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
CRO record update desired
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

16.3.1 Gather Follow-back Assignments

ID: 16.3.1
Description
Primarily the gathering of the follow-back needs that have been assigned to a particular field staff member. This would include all tracking and query information needed.
This process should also allow the transfer of any follow-back responses that are needed by the field staff. That is, if the disposition of a follow-back response is to send it to the field staff, this process should make sure the information is provided.
Interested Registries
Interested:
Not Interested:
Local Procedures

Degree of Automation
Semi
Processor
Field Staff (either a mobile abstractor type or a manager from home)
Location
CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)
Policies/Business Rules

Sensitivity

Trigger
Field Follow-back update desired
Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

16.3.2 Update CRO Follow-back

ID: 16.3.2
Description
Primarily, updating the follow-back tracking data stored in the CRO with the newly obtained/modified follow-back data stored on a laptop or a home computer. Hopefully, this is the response to follow-back as well as tracking information.
This also should allow for a field staff member to submit a follow-back request into the follow-back tracking system too.
Interested Registries
Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

CRO follow-back update desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

16.4.1 Gather Follow-up Assignments

ID: 16.4.1

Description

The gathering of the follow-up needs that have been assigned to a particular field staff member. This would include all tracking and query information needed.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Field Follow-up update desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

16.4.2 Update CRO Follow-up

ID: 16.4.2

Description

Updating the follow-up tracking data stored in the CRO with the newly obtained/modified follow-up data stored on a laptop or a home computer. Hopefully, this is the response to follow-up as well as tracking information.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

CRO Follow-up update desired

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

16.5.1 Gather AFL Assignments

ID: 16.5.1

Description

The gathering of the abstract facility leads that have been assigned to a particular field staff member.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

Field AFL update desired

Metrics

Frequency:
Volume:
Duration:

Quality/Error rate:

16.5.2 Update CRO AFLs

ID: 16.5.2

Description

Primarily, updating the AFL tracking data stored in the CRO with the newly obtained/modified AFL data stored on a laptop or a home computer. This should include the date abstracted or date attempted, potentially the reason not abstracted as well as any other changes made to the AFL.

This also should allow for a field staff member to submit a newly discovered AFL into the tracking system too. (Referred to, referred from facilities)

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO

Field Laptop (freestanding)

Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

CRO AFL update desired

Metrics

Frequency:

Volume:

Duration:

Quality/Error rate:

16.6.1 Update CRO Edit Tracking

ID: 16.6.1

Description

Since most registries try to track when a particular data item or rule is causing problems for their staff, it is important to be able to get edit result information from the field staff (as well as edits from the CRO).

DESIGN NOTE: for rate purposes, it might be better to collect a counter of the number of times a particular edit was run as well as the failures for that edit.

Interested Registries

Interested:

Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Field Staff (either a mobile abstractor type or a manager from home)

Location

CRO

Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
CRO Edit tracking update desired

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

17.0 Edit Patient Set Info

ID: 17.0

Description
This process includes checking existing data against rules. It includes checking a value against valid values for the data item and checking the data item value against other data item values (within and across CTCs) to see if there are any inconsistencies or conflicts. It would also check for any related override flags.
In order to do all editing (field, inter-field), this process needs the data item to be edited and the rest of the patient set to edit against.
This process NEVER makes changes, it just notes where problems are found and returns them to the calling process.
DESIGN NOTE: Registries believe they need to be able to run this process in batch mode – all patient sets that have changed during the day run through 17.0 during the night and a report of all problems found is presented in the morning. (would be nice as a back-up check, however, in new design edits should have been completed as patient set was worked on.)
DESIGN NOTE: would be nice to add option to allow org rep to choose how much of 17.0 is normally called. Any change to data should start 17.1 Field edits, but 17.2 inter-field edits is only truly needed after 2.1 Create Abstract, during 4.5.1 Incorporate All Info into Single Patient (end of consolidation), after 18.1 Compare and Resolve Text to Codes (visual edits) during 5.3 Establish Patient Set as Submissible (last thing prior to submission), and after 7.4.3 Select Best Value from Active Follow-up. However, some people may prefer being notified of problems as they go. The inter-field error notifications would have to be unobtrusive at points other than the ones previously listed.
DESIGN NOTE: 17.0 needs to be able to return some information as to the severity of the error. This may be attached to the edit rules or may have to be based on actual error. This may take the form of a weight. This should probably be easy to change. Possibly needs to be configurable.
DESIGN NOTE: The registries wish to have different levels of edits. That is, weekly edits which contain a specified subset of the edit rules, versus monthly edits which contain a larger subset, versus pre-submission edits which would contain all edit rules. The number of levels and exact subset within the levels should be configurable by registry and will probably change over time so it should be easy to modify at the registry.

Interested Registries
Interested:
Not Interested:

Local Procedures

ACoS edits in addition to SEER
State edits in addition to SEER: NM, CA, DT, CA

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

With computerized reports, edit reports are sent back to the data provider. They try to do this every time a batch is processed. (Probably out of 13.0)

Sensitivity

Trigger

Change in data value in patient set **or**
Edit needed (includes field edit desired **and** inter-field edit desired) **or**
Data Item Values Match (from 4.4.2.1)

Metrics

Frequency: LA & HI: as batch comes in; during/after consolidation; on SEER extract file prior to submission.
Frequency: Rules change yearly in LA
Volume:
Duration:
Quality/Error rate:

17.1 Compare Individual Value to Rules

ID: 17.1

Description

Verify that value (code or text) selected (or keyed) for a data item is actually acceptable per the rules (local, SEER, other). May be a valid format or actual value. (if possible values are 0, 1, 9; Q would fail this process. Telephone numbers are xxx-xxx-xxxx)
If the value fails, returns the status to the process which called editing and allows the value to be fixed there.
If the value passes, passes the valid data item to 17.2 Validate Value vs. Other Data Items.
Aka Field Edits
Should include noting missing value for critical data item.

Interested Registries

Interested:
Not Interested:

Local Procedures

Different registries probably have different standard values as well as some differences in data items. Local rules should be easy to interact with.

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger
Field edit desired

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

17.2 Validate Value Versus Other Data Items

ID: 17.2

Description
Verify that the value selected for the given data item is not in conflict with the value of other data items.
Aka inter-field and inter-record (inter-tumor)
Other data items include all items in the patient set. This would include checking values of the same data item name for different CTC sets, treatment sets, and so on. Would also include override flags.
Passes the item status back to the process which called 17.0 – either passed all edits or failed edit vs other data item with particular comparison which caused the problem. (Site failed the sex-site edit)
One type of rule: if a data item has changed, all recodes of said data item must be consistent (age, age recode; site, site recode; survival, etc)
One type of rule: if a data item has changed, all conversions of said data item must be consistent (ICD-O site, ICD-O-2 site, ICD-O-3 site; hist; EOD codes; Site specific surgery, etc)
Similar type of rule: if underlying data item is changed, may need to reassign other data items (address and census tract.)

Interested Registries
Interested:
Not Interested:

Local Procedures
Don Green says there are just errors. They may choose to leave the problem and set an override flag. However, the registries seemed to think there could be errors, warnings and inconsistencies. They were unable to articulate the difference. Seems to be that an Error is considered to be a black mark and warnings/inconsistencies don't look so bad.

Degree of Automation
Fully

Processor
Computerized

Location
Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules
Not all errors can be overridden. However, sometimes the 'errors' are really just extremely unusual combinations and if the other data for the patient set (text in abstract, follow-back and so on) support the value, the field may have an override attached.

Sensitivity

Trigger

Inter-field edit desired **or**
Inter-field edit also desired (from 17.1)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

17.3 Update Tracking

ID: 17.3

Description

Update the edit issue tracking.
Currently this process stores whether it was a facility error, the status of the edit issue (if it changes), the resolution, the resolution date

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Fully

Processor

Computerized

Location

Central Registry Office
Field Laptop (freestanding)
Field Registry Staff Home (logged in)

Policies/Business Rules

Sensitivity

Trigger

(edit issue is declared resolved, but that happens in the calling process)

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

18.0 Conduct QC Checks

ID: 18.0

Description

Compare text to the rules for deriving codes (i.e. what the coder put down).
Evaluate the derived codes against the currently assigned codes.
Resolve discrepancies.
Checking and may be changing data.
May identify 'Abstract Facility Leads'
Update 'changed data items tracking info.'
Check follow-back responses received with this process name in disposition to use in this process.
Dynamically create and submit follow-back request as needed.
DESIGN NOTE: Are there opportunities to make this more rule-based at best and, at least, make recommendations?
This is a Quality Control function.
DESIGN NOTE: Registries need to be able to send editing reports back to abstractors - errors in coding of abstract, prior to consolidation. SEE LA for ideas. (Editor is asked if change is error. At end of process, new

abstract is printed with changes in red. Report is sent by submission and some kind of monthly/quarterly basis.
This seems like an appropriate place to do:
Match patient sets to patient sets to verify no matches have been missed
Re-editing (visual edits) to make sure that problems aren't being missed and mistakes aren't being introduced during the editing process.
NOTE: may also be the correct place to 'Determine if Missing Critical Data Items' (currently 5.6), however, feels more like a polish task and can be automated.

Interested Registries
Interested:
Not Interested:

Local Procedures

Degree of Automation
Semi
Fully

Processor
Editor/Consolidator/Coder
Super Editor
Abstractor
Computerized

Location
Central Registry Office

Policies/Business Rules
Verifying the codes to the text is currently referred to as "Visual Editing". Would like to send edit reports back to the data provider (as is the case with computerized edits). They try to do this every time a batch is processed.)

Sensitivity

Trigger
See sub-processes

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

18.1 Compare and Resolve Text to Codes

ID: 18.1

Description
This is currently referred to as "Visual Editing", comparing the text to the codes that were assigned. (Making sure the words in the patient records match the codes in the database) This focuses on medical editing, for which training is required.
Checking and changing data.
After each change to the data, single field edits would occur. After all changes are 'complete', inter-field edits need to occur (they could be noted after every change, but have to be un-intrusive and can't prevent further edits. This would continue until all edits passed or were overridden.
Abstract Facility Lead may be caused by discovery of prior CTC that is not in the Patient Set
Errors, Warnings, and Inconsistencies are being processed here.
Verification of medical coding which has occurred at other points in the process path.

This would include editing of the Facility View of the patient set (aka an incoming abstract) prior to registry view consolidation.
Also includes the review of edits (patient set and add/change/deletes) by supervisors.

Design Consideration

They would like to be able to print out the patient set to review it instead of doing so on the computer (so that staff has the option). We need to allow a standard print format which mimics an abstract.
From medical coding point of view, the more drop down lists with text and corresponding code that can be added, the better. However, need to allow staff to start typing as well (some feel this is faster than pure drop-down)
While editing the facility view, they would like to be able to print out error reports for selected variables for the facilities or abstractors (in order to improve facility abstracting skills and reduce future errors). They need to be able to specify whether or not a change should be considered an 'error', as some changes may be made based on information they don't expect the facility to have.
DESIGN NOTE: Security of the changes made here are complicated. This process is restricted, but within the process, they further restrict what kind of changes can be made. For example, only select people can change vital status from dead to alive or back date a date of last contact value.

Interested Registries

Interested:
Not Interested:

Local Procedures

California registries are most interested in having the ability to count errors on specific data items on incoming abstracts. (email from J.Boone, 4/30/02)

In depth review of abstract, patient set and related material:
- AT, HI, IA, NM: trainees work is reviewed for several months (hospital and registry staff)
- IA: reviews a random sampling of work.
- DT: 8 random cases per editor are reviewed

Degree of Automation

Semi

Processor

Editor/Consolidator/Coder
Super-Editor
Abstractor

Location

Central Registry Office

Policies/Business Rules

A different ORG REP may do the compare than the ORG REP who does the resolve (for training or because of overburdened staff). While the registries NEED to track who makes changes to the patient set, they are not as interested in who edited the patient set. They seemed to feel that a note in the comments was probably enough. They felt a specific tracking mechanism for who edited (separate from who changed) would overburden the staff and the computers.

Sensitivity

Trigger

Entire consolidation completed **and**
Visual editing desired

(Edit Complete)
(Follow-back Complete)

Metrics

Frequency: LA & HI: ongoing, happens during consolidation
Volume: LA: **spawn most follow-back here, but just call them**
Volume: LA, HI, DT, UT, NM, IA do 100% of their CTCs normally.
Volume: AT: 100% of SEER cases, 100% for employees of 6 mths or less, but does not have the staff to do 100% of all CTCs. (would like to)
Duration:
Quality/Error rate:

18.2 Delete Patient Set Info

ID: 18.2

Description

If during an editing process, the staff member determines that the information they are reviewing is not reportable, they can 'delete' the information (entire patient set, facility view, CTC set, treatment set).
Should store new status, date deleted, reason and staff id deleting.
NOTE: Delete really means change the status to non-rpt. Would want to keep for audit purposes and to prevent accidental re-creation.
Can mark statuses and delete information at different levels.
Can delete patient sets.
Can delete CTC sets. (If the only CTC of that patient, the patient set can be deleted.)
Can sometimes delete a facility view only.
Can delete treatment information.
Should mark edit issues related to the deleted set 'deleted' (don't actually delete them)
Association to health records is maintained as it's moved to the "deleted patient set" data store (or whatever it will be called).
DESIGN NOTE: It is likely that only select people can do this process, probably a smaller group than can do the other 18.0 processes.

Interested Registries

Interested:
Not Interested:

Local Procedures

LA: only currently makes this decision during initial processing of abstracts.
NM: only senior editors can do this task.

Degree of Automation

Semi

Processor

Super-Editor
Editor

Location

Central Registry Office

Policies/Business Rules

Registries never truly delete anything. This information is retained with 'deleted' flag for QC purposes (if someone asks why this CTC isn't in database, want to be covered)

Sensitivity

Trigger

Need to "delete" patient set info

Metrics

Frequency:

Volume:
Duration:
Quality/Error rate:

18.3 Conduct Patient Set-to-Patient Set Matching

ID: 18.3

Description

A.k.a. duplicate checking
In an effort to keep the database clean, periodically the patient sets are matched to the other existing patient sets to verify that only 1 patient set exists per person.
This is necessary because sometimes the original incoming information does not appear to be a match, but later updates/corrections to the information may indicate that a match exists (ie Jack Smith, SSN 123-45-6789 could change to John E. Smith, SSN 123-54-6789)

DESIGN NOTE: If a patient A is determined to be the same as patient B, the following happens: One patient set is noted to be a duplicate (say B). B is retained in the database for historic purposes. All MATCHs to Patient B are updated to be rejected with the reason being patient set duplication with patient A. New MATCHs are formed to Patient A. Patient B information is consolidated with Patient A with the ACD tracking changes made because of the patient set duplication. If the patient sets every need to be split apart again, the following will then be easily accessible: Patient A at time of merge; Patient B at time of merge; MATCHs to Patient B; ACDs to Patient A after the merge (some of which may truly belong to patient B).

Also CTC to CTC matching. This matching would occur within a single patient only, especially if a patient set to patient set match was discovered.
This process includes 4.0 Match & Consolidate Patient Set Info just using patient sets, not the rest of the data. If no match is found, exit the process. Otherwise, consolidate, etc as noted above.
They want to make very sure that this is a true match before consolidating the patient sets.
DESIGN NOTE: Need to allow NAACCR specific algorithm to be performed here. NAACCR requires that a random sample of CTCs be tested for duplicates based on zip code, sex, dob and (?) race. Rate must be less than 1 per 1000. Exact algorithm found in “NAACCR duplicates.doc”, this directory (extracted from NAACCR home page).
DESIGN NOTE: it’s likely that the registries will want additional matching algorithms for this task.
DESIGN NOTE: This need not happen at the same time as 18.1.
DESIGN NOTE: bear in mind that sometimes these patient sets need to be split apart later – make it easy to undo the merge back to the state each patient set existed in prior to this consolidation.

Interested Registries

Interested:
Not Interested:

Local Procedures

In HI, this is done using regular matching techniques as well as the NAACCR blocking
In Seattle, this match is based on:
SSN
first 5 chars of last name, first initial DOB
sex, first name, DOB

first 4 chars in address field, county
first name, site, dx year, county
dx mth, dx yr, hist, patient name
partial name keys, birth mth, birth y
last name, sex, birth y
first name, sex, first 2 digits of site
NAACCR linkage rules.

Degree of Automation

Fully

Processor

Computerized: batch job – for all patient sets (or some sub-set of patient sets), take patient set and match against all others. Consolidation would have to wait for human intervention.

Location

Central Registry Office

Policies/Business Rules

When a match is found, consolidation occurs. The oldest patient set should probably be the 'base' patient set for consolidation purposes.
NAACCR requires the NAACCR duplicate-checking algorithm to be used (and results reported) for NAACCR certification. Algorithm is probably on their web site. (Harvey Diehl, IA has local implementation.)

Sensitivity

Trigger

Single patient matching **or**
Entire database matching desired

Metrics

Frequency: LA: quarterly; HI: NAACCR style at submission time, regular matching ongoing
Volume: AT, LA, HI, DT, UT, NM, IA do 100% of their CTCs normally.
Finding very few (LA: 50 over DB)
Duration:
Quality/Error rate:

18.4 Assess Likelihood Treatment Complete

ID: 18.4

Description

Review Seattle's algorithms

Given that you have a certain site, type, stage of CTC for a person of a certain age with given comorbidity status, residency in Hospice, determine the likelihood that the treatment you have knowledge of is complete. This would be based on standards of treatment care for that CTC in that age, CTC type and comorbidity status.
The registry is trying to determine if there is missing information and if so, follow-back would be initiated to determine where the other treatment should have come from or why is was not given.
Would be performed on registry view.
DESIGN NOTE: if this is automated, would need to allow for easy modification of treatment specifications (which change as new knowledge and protocols are developed in the medicinal world). Would also need to set an override flag so that a particular CTC set can be ignored once follow-back is completed.
DESIGN NOTE: UT & HI mentioned that they believe Seattle registry has the rules that would drive this already automated! Since (as far as I've heard) Seattle is the only registry doing this, we should talk to them before attempting to design this process.

DESIGN NOTE: Seattle mentioned that it would be nice to have flags for Patient, CTC and for each treatment modality that for that Patient (or Patient/CTC or Patient/CTC/modality) that you want to stop queries. For example, if a patient dies in the middle of surgery, wouldn't want to query why radiation wasn't done. These could be stored as flags on the patient or a series of local rules about when letters about missing treatment should not be sent which are accessed for every patient set run through 18.4. Seattle uses national treatment standards and mitigating circumstances to determine what would be reasonable for a particular CTC.

Interested Registries

Interested:
Not Interested:

Local Procedures

In Seattle, a failure here would spawn a physician data query (PDQ) about the treatment the patient received and why it isn't complete.
In Seattle, this is only done if a new health record is received for the patient. (A new admission. They assume that the abstractors acquired all information possible from the medical records when the abstract was done. They don't want to bug them to review the records unless they have cause to believe that new information is available.)
In Seattle, if they determining that a casefinding record has a Patient, Facility and CTC match, they do this process to determine if more information should be acquired from the facility. This would lead to 8.0

Degree of Automation

Semi
Would like to be fully automated, with notification to Editor: see Seattle

Processor

Abstractor
Editor/Consolidator/Coder
Computerized

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Need to assess likelihood treatment complete

Metrics

Frequency: HI: believes protocols change less than annually
Volume:
Duration:
Quality/Error rate:

18.5 Split Patient Set Info

ID: 18.5

Description

If it is determined that within one patient set, 2 separate people are being described (the infamous twins) or within one CTC set, 2 separate CTCs are being described (simultaneous primary), the information is separated into two sets as needed.
This task is fairly time consuming and a pain to do. They would need to have all source records available. This spawns 'Rejected Match' at some level which they need to track so the data isn't recombined later. It would also involve creating new match links to the 'split' patient set. May

want to create 'Same patient' type match with rejected status for future runs of 18.3

DESIGN NOTE: if the split is to a patient set that used to be 2 patients sets and was combined via 18.3, if the computer could automatically back the 2 patient sets up to their set pre-consolidation and note any changed made after the date of the match being accepted. Alternative would be to have the patient set that was merged saved with a special status flag so that all its' information was readily available at it existed at the point of merge. All other changes to the patient after the consolidation would have to be reviewed and applied to the correct patient set manually.

This process is similar to Consolidation and may need to use the same screens.

DESIGN NOTE: It is likely that only select people can do this process, probably a smaller group than can do the other 18.0 processes.

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Semi

Processor

Super-Editor
Editor

Location

Central Registry Office

Policies/Business Rules

Sensitivity

Trigger

Need to split patient set info

Metrics

Frequency:
Volume:
Duration:
Quality/Error rate:

<PROCESS NAME>

ID:

Description

Interested Registries

Interested:
Not Interested:

Local Procedures

Degree of Automation

Processor

Location

Policies/Business Rules

Sensitivity

Trigger

Metrics
Frequency:
Volume:
Duration:
Quality/Error rate:

Sources/Sinks

ABSTRACTORS

Description
People who create abstracts
Here, SEER org reps who review medical records and summarize the information into abstracts for the registry.
Location subtype would be Mobile Abstractor Laptop, Registry Staff Home and sometimes Central Registry Office for Registry Abstractors.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Metrics
Volume:

DATA EXTRACTION RULES

Description
This represents any Local, State and/or Federal rules regarding data extraction, such as privacy rules. Includes HIPAA restrictions.
Who can have information, what kind of information they can have, what safeguards/legal requirements must be met before data is releases, so on.
Physician may get information about his patients, but not about other patients. Research group may receive information after signed collaborators agreement is on file and IRB has approved use of data.
May also include registry based decisions (so and so can't receive data from registry because of past experience.)

Interested Registries
Interested:
Not Interested:

Local Procedures
Varies by registry as different state and local rules apply

Policies/Business Rules

Sensitivity

Metrics
Volume:

DATA MANAGER

Description
Owner of account id's and passwords, e.g. for allowing access to Registry-Controlled Files.
Registry org rep. (may be done by computer)

Interested Registries

Interested:

Not Interested:

Local Procedures

How accounts/passwords are set up may vary by registry.

Policies/Business Rules

Sensitivity

Metrics

Volume:

FACILITY

Description

A location where health care services are provided

A specific facility a Registry interacts with. Usually some place the registry is getting health, follow-up and follow-back information from. In cases where facility has a cancer registry, the registry probably sends information back. Facilities can also make intermittent requests.

Location subtypes include Hospital Cancer Registry, Other Provider, and Hospital Record Dept (although not all of these are within a facility).

They may also be a Data User Location

Types include:

- Hospital
- Lab
- Treatment Center (ex.: radiation, chemo, oncology)
- Day Surgery
- Doctor's Office
- Nursing Home
- Hospice
- Coroner's Office
- Cancer Center
- …

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Need contact information from: name, address, person to contact, (department), phone, fax, e-mail. This information is stored in the Org, Facility and Medical Practitioner Profile.

Larger facilities may have multiple people to contact as they contain multiple departments.

Sensitivity

Metrics

Volume:

HOME COMPUTER

Description

A computer owned by a registry staff member, located in their home.

Only of importance for those staff members who periodically need to interface with the central registry data bases.

Most likely, these are managers' computers.

NOTE: this used to be included in 16.0 Exchange Registry Data, but it was decided that interaction between a home computer logged into the central registry and the central computer would need to be handled within the processes and not in 16.0

Interested Registries

Interested:

Not Interested:

Local Procedures

IA: the field staff in Iowa works from home, so they would also have to be able to connect to and exchange data with the CRO system.

Policies/Business Rules

Sensitivity

Metrics

Volume:

IRB

Description

Institution Review Board: this represents the actual meeting where the institution's desire to allow a special study or information request to make use of their data occurs. The decision and any comments are recorded and sent to the registry.

The results are stored in IRBs data store. Definitely need Institution ID, Date of review, approved/denied. May need members.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

For special studies, the registry is probably not requesting the IRB approval, nor are they directly receiving the response. However, we assumed they would like to be informed (probably as the contract is being written) and would store that as well in the IRBs data store.

Sensitivity

Metrics

Volume:

INFORMANT

Description

Anyone who has knowledge of the patient

Could be Registry Staff person, relative, guardian, or neighbor. Mostly used to do Active Follow-up, but in cases of Do Not Contact Patient, informant may be used for other information gathering.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Try to obtain an informant in case it's inconvenient or unacceptable to contact the patient directly.

Sensitivity

Metrics

Volume:

LAPTOP

Description

A laptop computer owned by the registry, used by a registry field staff member, who periodically needs to interface with the central registry data bases

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Metrics

Volume:

LOCAL RULES

Description

Each registry has a set of local rules which is a merged view of all local organization rules
Rules that the registry has decided upon to help them do business. (i.e. Seattle's abstractors don't code, coders don't abstract type)
Rules that the registry must follow to enable them to report data to the different groups they have responsibilities to (CDC, State, NPCR, so on)
Rules that are based on local restrictions (State law, agreements with facilities or organizations)
Rules about patient inclusion in special studies, especially those requiring patient interviews
Rules for determining whether or not a person is eligible for active follow-up, whether they would have priority in this task, and the preferred methods are for obtaining this information (contact doctor by letter first, patient contact as last resort and only by phone, etc)
DESIGN NOTE: Active FUP rules can be quite complicated. Seattle has a matrix of rules by facility.
Rules from the state concerning data submission requirements for the facilities and organizations. See State Relations data flow
Would include rules about how to edit local data items and rules about standard coding scheme. Would need tables for conversion purposes at least. (NOTE: this would include the US Dept of Ag table of rural/urban continuum – state/county FIPS code assigned a continuum code.)
Edit rules would need to have some kind of severity mechanism attached for editing an incoming submission. The registry may decide to reject all or some portion of a submission based on the severity. This would be effective in 13.3
Rules for determining when a letter about missing treatment should not be sent – see Design Note in 18.4
DESIGN NOTE: The registry staff need to be able to easily view these rules. If they discover a problem, they need to be able to check the rules to see if they are causing the problem and change them as necessary.
Rules determining which records are reportable or not.
DESIGN NOTE: in some registries, screening rules vary by institution (how accurate are the record coders for that institution, what kind of words to they use, etc).
DESIGN NOTE: Edit rules (17.0) The registries wish to have different levels of edits. That is, weekly edits which contain a specified subset of the edit rules, versus monthly edits which contain a larger subset, versus pre-submission edits which would contain all edit rules. The number of

levels and exact subset within the levels should be configurable by registry and will probably change over time so it should be easy to modify at the registry.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Must be implemented at the registry level and so should be easier to access.

Edit rules would need to have some kind of severity mechanism attached for editing an incoming submission. The registry may decide to reject all or some portion of a submission based on the severity.

Sensitivity

Metrics

Volume:

MEDICAL PRACTITIONER

Description

Someone who is licensed to practice medicine

Possibly someone the registry gets health, follow-up or follow-back information from.

May be associated with multiple facilities (physician with a practice – doctor's office – who has admitting rights at a hospital)

Could be a physician, nurse practitioner, physician's assistant, …

Can diagnose

Can order treatment

Could potentially perform the treatment

Can take a specimen

…

Interested Registries

Interested:

Not Interested:

Local Procedures

Need some way to identify medical practitioners (especially physicians). May be license or registry assigned identification number.

Policies/Business Rules

Would want to track name, license number, address, phone, preferred method of contact, preferred time of contact, do not contact. This information is stored in the Org, Facility and Medical Practitioner Profile.

Sensitivity

Metrics

Volume:

ORGANIZATION

Description

A political or economic entity

A specific organization a Registry interacts with. Usually some place the registry receives health, follow-up or follow-back information from or some place they routinely send data to. Other organization may ask for data intermittently.

Location subtypes include Other State Registry, Intra-State Registry SEER Office, Supplemental Data Source, and some Hospital Record Dept (those which are contained external to the hospital). They may also be a Data User Location

Organization types include:
- State Health Departments
- SEER Registries
- State Registries
- Hospital Registries
- Other Registries
- Department of Motor Vehicles
- Insurance Companies
- News Organization
- Credit Agencies (Equifax, …)
- HCFA
- Social Security Administration
- Indian Health Services
- SEER (NCI)
- State
- American College of Surgeons
- NAACCR
- CDC
- Hospital
- Local agencies
- …

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Need contact information for these: name, address, person to contact, phone, fax, email, so on. This information is stored in the Org, Facility and Medical Practitioner Profile.

Sensitivity

Metrics

Volume:

ORGANIZATION REPRESENTATIVE

Description

A person working for or representing an Organization

AKA staff member.

Any given person may represent multiple organizations at different times. For example, some of the registry abstractors (in that capacity, a SEER registry org rep) moonlight as abstractors for the various facilities (in that case, a facility org rep)

While this is usually an external organization, this also represents SEER staff members.

For a SEER Org Rep, location subtypes may be Central Registry Office, Mobile Abstractor Laptop or Registry Staff Home.

For other organizations representatives, the locations would be the same as for organization.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Only authorized SEER org reps are allowed to do certain tasks.
Would need to track to registry org reps what tasks they are authorized to do.

Sensitivity

Metrics

Volume:

OTHER RULES

Description

Rules other than local or SEER that the registry may have decided upon for editing and how text should be translated into codes.
This may vary by hospital/physician and may be hard to codify.
Also would include which words were important and for vague words which ones should be considered to indicate cancer/tumor.
For example, how disease text should be shown in ICD site, hist, beh codes, how staging information should be captured.
For example, registry may prefer to believe hospital A values over hospital B values based on past experience. When a registry chooses to override an editing error.
DESIGN NOTE: Edit rules (17.0) The registries wish to have different levels of edits. That is, weekly edits which contain a specified subset of the edit rules, versus monthly edits which contain a larger subset, versus pre-submission edits which would contain all edit rules. The number of levels and exact subset within the levels should be configurable by registry and will probably change over time so it should be easy to modify at the registry.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Edit rules would need to have some kind of severity mechanism attached for editing an incoming submission. The registry may decide to reject all or some portion of a submission based on the severity.

Sensitivity

Metrics

Volume:

PATIENT

Description

A person who has developed a cancer/tumor/case and is therefore of interest to the registry.
Registries interact with patients to:
Obtain follow-up
Obtain Follow-back (? Much less frequently)
Obtain consent to participate in interview for special study.

Location subtypes is Patient Residence, the place at which contact may be made with a patient.

Interested Registries

Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Metrics
Volume:

PERSON

Description
A human being interacting with the registry who is not currently (within the interaction) of interest to the registry.
Could be researchers, info requesters, etc.
Physicians and patients who do not identify themselves as such would also be included here.
Specifically, someone who has presented an information request to the registry, is supposed to receive the request fulfillment or who has a problem with the request fulfillment.
Location subtypes is Data User Location, place where data user can be contacted.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules
Probably only of interest for duration of the information request.
May have more restrictions on what information the registry is willing to provide to them. Would have to receive IRB approval in some cases.

Sensitivity

Metrics
Volume:

SEER RULES

Description
Rules determined by NCI SEER specifically (reportable disease list) or indirectly (information that needs to be obtained or how it needs to be coded in order to meet the submission criteria for SEER: what needs to be known to obtain EOD staging)
Includes rules for when date of last contact expires and how to deal with patients for whom follow-up is not obtainable.
Includes rules about field, inter-field and text-to-code type editing. The interfiled edits have been provided to the registries in programmatic form already.
DESIGN NOTE: when SEER changes a rule, they have to be able to support the old rule (for CTCs diagnosed before the rule change).
DESIGN NOTE: Edit rules (17.0) The registries wish to have different levels of edits. That is, weekly edits which contain a specified subset of the edit rules, versus monthly edits which contain a larger subset, versus pre-submission edits which would contain all edit rules. The number of levels and exact subset within the levels should be configurable by registry and will probably change over time so it should be easy to modify at the registry.

Example
If there are multiple diagnoses of one cancer/tumor/case, the earliest diagnosis date is the one of interest to SEER.

Interested Registries
Interested:
Not Interested:

Local Procedures

Policies/Business Rules

Registry wide, should be no variation among the registries.
Can be changed centrally
Edit rules would need to have some kind of severity mechanism attached for editing an incoming submission. The registry may decide to reject all or some portion of a submission based on the severity.

Sensitivity

Metrics

Volume:

SPECIAL STUDY

Description

A research project which has asked a registry to gather it's data. In most cases, this is data the registry collects anyway, but the collection process may be sped up. Additional variables may be collected or additional diseases might be of interest.
Paid for separately from SEER.
See data flow 'Special Study Tracking Info' for total picture. Information from here would include: start date; end date; contact person; study name; study id (might be registry assigned); site/hist/beh codes of interest (criteria for selecting cohort); rapid case ascertainment flag; interview desired flag; list of desired variables; criteria for data contained in non-standard variables; number of desired patients. Registry may wish to store this in special study tracking data.
After the special study has gotten data from the registry and has commenced the study, the registry may wish to obtain information from the study such as: list of patients actually included in study (may be different from those sent); patient set information that the special study has obtained (through interviews, through other sources, so on); information on new cancer/tumor/case that the special study obtains. This would have to be stated in terms of special study contract.
Special study may have follow-back questions that occur as they work with the data they receive. These must be routed through the registry.
Location subtypes is Data User Location, place where data user can be contacted.

Interested Registries

Interested:
Not Interested:

Local Procedures

Some registries contact the physicians to get approvals for special study participation themselves, some allow the special studies to do so.
Registries have different guidelines on how many times and how often any given patient can be included in a special study that desires an interview.

Policies/Business Rules

IRB approval is required for ALL special studies: DT, IA, LA, HI, UT, NM, AT
Special studies have to be approved.
Approval must be gained before patients can be contacted.

Sensitivity

Metrics

Volume:

STATE

Description
The state that the registry resides in.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Metrics
Volume:

SURNAME PROGRAM

Description
A program used to help verify Ethnicity. It returns a possible Ethnicity Code based on Patient's Surname.
The rest of the patient's name (first, middle, etc) and Marital Status, Race, Gender, State, County may also be used to determine ethnicity or modify the certainty score.
Interested Registries
Interested:
Not Interested:
Local Procedures
Ethnicity assignments may be based on location of registry.
Currently, some registries are using the GUESS program for this.
Others have made their own, more specific, program. (not sure if this is outsourced)
ATL: uses Asian Surname program (in addition to standard). They don't run it often and it is very old.
Policies/Business Rules

Sensitivity
April Fritz (NCI) mentioned that the Asian surname program was removed from the website because there was concern among people with the names that their name was being associated with cancer.
Updating the surname lists is in the queue, but is not a priority to NCI.
Metrics
Volume:

SYSTEM

Description
The computerized registry operations
The network or workflow or whatever implementation is chosen to encompass all registry operation processes, databases and 'the computer' concept.
Interested Registries
Interested:
Not Interested:
Local Procedures

Policies/Business Rules

Sensitivity

Metrics
Volume:

TYPE OF MEDIA

Description

The type of media the registry has available to use when fulfilling information requests.

Probably could also contain the type of media the registry is able to handle.

For example:

- Paper
- FTP
- Tape
- Diskette
- Post Card
- Email
- CD-ROM
- Web Page
- Phone
- Virtual Private Network (VPN)
- Scanned Image

Interested Registries

Interested:

Not Interested:

Local Procedures

Types vary by registries.

Since extracts files are typically very large, they would more likely use media that can handle large amounts of data (CD-ROM, tape, etc)

Since reports are generally small, they would more likely use media that may have size restrictions (paper, phone, post card, email, web page, scanned image, etc)

(Registry-controlled files aren't released, so wouldn't be on any media)

The exact type of media used for any given request depends on what media was requested, what media is available, the amount of data to be transferred and probably the personal preference of the org rep fulfilling the request. Also, if the fulfillment is an existing report or extract, there may be a media already in place (annual report is printed, they would just mail a copy)

Policies/Business Rules

Sensitivity

Metrics

Volume:

VITAL STATISTICS BUREAU

Description

When a registry discovers a patient in their database or a patient of interest has deceased, the registry goes to the Vital Statistics Bureau to obtain their death certificate.

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Metrics

Volume:

<SOURCE/SINK NAME>

Description

Interested Registries

Interested:

Not Interested:

Local Procedures

Policies/Business Rules

Sensitivity

Metrics

Volume: